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Enhancing Patient Engagement in Pulmonary Healthcare

The Art and Science

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Preface

Effective engagement of patients with pulmonary disease in their healthcare is an integral component of comprehensive management. When communication and conscious engagement strategies are neglected, it can lead to nonadherence to medical regimens and healthy behaviors, resulting in poor individual and societal outcomes such as new-onset illness, disease progression, suboptimal health-related quality of life, and spiraling healthcare costs.

As healthcare professionals, we focus mainly on identifying and understanding the pathophysiology of disease to effectively treat illness, but this approach is entirely inadequate to treat the patient. The patient is a person with unique perceptions and beliefs—interacting with the societal framework in which they live and work—all of which affect how they experience their illness and engage in their healthcare. Current healthcare models, while certainly improved from the former paternalistic, acute care model, remain woefully inadequate in capturing the complexity of the individual patient. Without this understanding, a true partnership in care is unlikely.

It is vitally important that we engage the patient as a partner. This book originated from our desire to examine and better understand the moment after a patient walks out of the office and the healthcare professional wonders if the patient will do what was instructed when he/she gets home. Were instructions clear enough? Did the patient understand why and how? What else could have been done to increase the chances of engagement in healthy behaviors at home? How can we avoid adding to growing piles of maintenance inhalers, unused CPAP masks sitting by the bedside, and oxygen tanks standing by the doorway? Patients are more likely to adhere to treatment when they believe it will improve disease control or when they can anticipate serious consequences related to non-adherence. As healthcare professionals, we play a critical role in helping patients understand the nature of their disease, the potential benefits of treatment, and most importantly, encourage them to take ownership of their disease by utilizing effective self-management strategies.

In this edition, we explore the complex concepts of patient engagement and behavior change across the spectrum of pulmonary healthcare. There are undoubtedly multiple factors underlying poor patient engagement. These include socioeconomic factors, health system and provider factors, disease-related factors, therapy-related factors, and patient-related factors. While all these factors are important, patient-related factors, including knowledge, learning, self-efficacy, cognitive ability, motivation, and psychological issues, are the focus of this publication. The chapters included in this book are state-of-the-art reviews written by leading experts in the field. Our common purpose is to better understand the scientific principles that form the foundation for patient engagement and apply successful treatment strategies to optimize both extrinsic and intrinsic motivation to ensure patients' long-term commitment to their health.

Chapter 1 provides an overview of the concepts of patient engagement, health behavior change, and disease self-management, and allows the reader to appreciate the evolution of our understanding of the complex factors that play a role in adherence. Chapters 2, 3, and 4 examine the theoretical basis for learning and educational design to engage persons in making meaning of information in a way that inspires application of the learnings in their daily lives. The next series of chapters provide tools to implement best practice with discussions of self-efficacy (Chapter 5), motivational interviewing (Chapter 6), cognitive behavioral therapy (Chapter 7), the use of technology to enhance physical activity promotion (Chapter 8), and a discussion of mind-body approaches to enhance healthcare engagement (Chapter 9). While these techniques are diverse, they all provide opportunities to enhance the patient–provider relationship.

The last five chapters provide practical implementation strategies of patient engagement techniques in settings that are common to the pulmonary patient. Chapter 10 focuses on adherence to use of supplemental oxygen while subsequent chapters address COPD self-management (Chapter 11), noninvasive ventilation (Chapter 12), correct inhaler use (Chapter 13), and smoking cessation (Chapter 14).

On reflection, we have much work to do to engage both the patient and healthcare professional in the process of facilitating positive health behavior change. Until we understand and effectively implement strategies to optimize motivation and behavior, we will find it a challenge to ensure our patients are adequately supported by us to achieve the best possible outcomes from their healthcare journey. Increasing our ability to effectively engage patients in their self-care is likely to have a far greater impact on the health of the population than any improvement in specific medical therapies. The potential rewards for both our patients and society are great.

We thank each of the authors for their participation and their efforts to push the envelope in our understanding of how to interact with patients to optimize engagement, adherence, and ultimately health. We look forward to future research in these areas and wider application of these treatment modalities. It has been a pleasure to serve as editors and a distinct honor to oversee such impactful work that brings a unique and much-needed perspective to pulmonary healthcare.

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Chapter 1
Defining Patient Engagement, Health Behavior Change, and Disease Self-Management

Jean Bourbeau

Introduction

Chronic diseases are the leading causes of death and disability worldwide, including cardiovascular disease, cancer, and chronic obstructive pulmonary disease (COPD) [1]. For chronic conditions, behavior change is a critical element of the therapy. The person with the medical condition is directly responsible for navigating complex daily routines and tasks. Self-management includes taking medications, monitoring and controlling symptoms such as dyspnea, preventing or minimizing negative side effects, and just feeling well. Consequently, effective self-management involves behavior change to be initiated or maintained.

Recognition of the growing threat of chronic disease should prompt changes in healthcare delivery to promote and support better patient engagement and self-management. Use of the Chronic Care Model, a practice transformation facilitating the delivery of patient-centered, evidence-based care, has been associated with improved health outcomes among patients with chronic disease [2, 3]. Self-management is a major component of the Chronic Care Model [4] within the context of the healthcare delivery system. The Chronic Care Model uses evidence (e.g., care standards, clinical guidelines) to provide quality care and information systems to improve communication and coordination among professionals, provide timely reminders and feedback, and monitor the effectiveness of individual care. Self-management interventions as part of the Chronic Care Model can largely reduce the negative physical and psychological consequences of chronic disease. However,

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to be successful, there is a need for patient engagement; it is increasingly recognized as an important factor in improving health outcomes, improving healthcare experiences, and reducing costs [5, 6].

Optimal care for chronic disease should include activities to support patients in self-management, including goal-setting and counseling patients to adopt healthy behaviors and to integrate skills at managing their disease on a day-to-day basis. However, without patient engagement, we cannot expect the intended benefits. There is also substantial evidence of the critical role that healthcare professionals can play in influencing levels of patient engagement among those with chronic diseases. Findings of improved outcomes among more engaged patients and use of care approaches employing a more participatory model of patient decision-making have been reported across a range of chronic diseases, including COPD [7–9].

This chapter will include the following topics of interest: problem of adherence in chronic respiratory diseases, strategies to improve adherence, and the importance and need to promote and support better patient engagement, e.g., behavior change and self-management. The chapter will take examples from one of the most common chronic respiratory diseases, COPD.

Adherence in Chronic Respiratory Disease

The Problem of Adherence

Management of chronic diseases such as asthma and COPD takes place at home, with patients and their family members. The negative physical and psychological consequences of chronic disease can largely be reduced with optimal self-management. Decisions are made every day by patients as to whether to engage in medical treatments and/or healthy lifestyle, e.g., patient's behavior. The process and outcome of decisions about treatment are defined as adherence.

In chronic respiratory diseases, patients have to be adherent to a care plan, adopting health behaviors such as smoking cessation, being physically active, and also behaviors that are specific to their medical condition such as taking medication, monitoring, and managing dyspnea and exacerbations. Nonadherence to treatment such as medication is well known in chronic respiratory diseases. Non-persistence of medication therapy, i.e., stopping after starting long-acting bronchodilators can be as high as 2/3 of the patients as reported in two studies in COPD [10, 11]. Nonadherence is not only about non-persistence in following the prescription but it can also be about using treatment in excess of what is prescribed. Overreliance can be seen and can be a problem, especially in chronic respiratory diseases with short-acting bronchodilators, a marker of poor disease control in airway disease [12]. Another important adherence problem is the poor handling of the inhaler or technical errors in using the inhaler; on average more than two third of the patients make at least one error when using an inhalational device [13]. For example, the most frequent metered dose inhaler errors were in coordination (45%; 95% CI, 41–49%), speed and/or depth of inspiration (44%; 40–47%), and no post inhalation breath-hold (46%; 42–49%) [14].

In COPD, inhaler misuse is associated with increased risk of hospitalization (OR 1.47), emergency department visits (OR 1.62), and oral corticosteroid or antimicrobial use (OR 1.50) [15]. Incorrect inhaler use in patients with chronic respiratory disease is still unacceptably high outside clinical trials and does not seem to have improved over the past 40 years [14]. This has the potential of being a major obstacle for achieving good disease control. Patients with incorrect inhaler use are at higher risk of having COPD exacerbations. It has been demonstrated that patients who had ≥1 critical error compared to those with no error were more likely to have COPD exacerbations in the previous 3 months, 38.5% compared to 32.1% risk of moderate exacerbations (requiring oral corticosteroids and/or antibiotics), and 6.9% compared to 3.3% risk of severe exacerbations (requiring hospital admission) [13]. These statistics highlight the essential role adherence can play in health status and demonstrate the importance of supporting patients with the development of their adherence. This can be overcome if patients are taught about correctly taking their inhalers, and therefore engaging patients in self-management and adherence.

Management of chronic respiratory disease requires more than just taking medication. The importance of non-pharmacological treatment has been recognized and should be part of the comprehensive management of any chronic disease [16, 17]. However, nonadherence is also a well-known problem for non-pharmacological treatment. Healthcare professionals have to emphasize patients' being in a smoke-free environment, taking vaccinations, having a written action plan in which the patient is properly coached on problem-solving and decision-making in the event of an exacerbation, and promoting healthy lifestyle habits such as exercise and physical activity. The content of these educational messages will vary depending on the patient's disease. For some patients, the emphasis will have to be on smoking cessation, to implement environmental remediation and avoidance measures, and to promote physical activity; for other patients with more advanced disease, the emphasis will be to implement an exercise program under supervision and adhere to long-term oxygen therapy. However, nonadherence is also highly prevalent for non-pharmacological treatment. For example, 52% of all environmental remediation advice is not implemented [18], 79% of patients fail to complete home exercise programs after completing pulmonary rehabilitation [19], and 30–55% do not use their home oxygen [20].

Strategies to Improve Adherence, e.g., Initiate or Maintain Behavior

Strategies to improve adherence should be an essential part of the clinical practice. Nonadherence could be unintentional or intentional. Unintentional nonadherence refers to the patient not having an understanding of the disease or treatment regimen

Table 1.1 Important differences between traditional "patient education" and "self-management education"

Patient education	Self-management education
Compliance-driven	Adherence-driven
Goals/problems/challenges identified by healthcare professionals	Goals/problems/challenges identified by the patient
Information/advice is disease-specific	Information/skills are problem-specific
Theory: knowledge = behavior change	Theory: confidence = behavior change

Adapted from Bourbeau et al. [21].

or not having structures in place that remind when a dose is due. To that end, strategies to address unintentional nonadherence will focus on patient education, simplification of regimens, and structures for remembering medication or other treatments.

However, strategies that focus on unintentional nonadherence are ineffective in the context of intentional nonadherence; in these contexts, multicomponent, patient-centered, psychotherapeutic approaches such as motivational interviewing and communication have been proposed. The hallmarks of effective strategies to improve intentional nonadherence are patient engagement, shared decision-making, and self-management. Patients and their families must learn to engage in self-management activities that promote health, prevent complications, and ensure patients' involvement in daily management decisions.

For this to be effective, it is essential to move from a traditional "patient education" to "patient self-management education." There are important differences between traditional "patient education" and "patient self-management education" as shown in Table 1.1. Behavior changes such as lifestyle (e.g., smoking cessation, physical activity) or integrating self-management skills (e.g., medication adherence, inhaler technique, being able to recognize an exacerbation, and using an action plan appropriately) to manage the disease on a day-to-day basis need more than "simple" education. Self-management, unlike traditional education, is patient-centric and encourages patients to effectively incorporate disease knowledge, use self-management skills, and develop problem-solving strategies, in order to more fully participate in treatment decisions and better cope with their disease. If done well, this approach can lead to greater patient motivation and confidence in their own ability to manage the day-to-day challenges of living with chronic airway disease such as COPD [21].

Self-Management and Health Behavior Change in Chronic Respiratory Disease

Definition of Self-Management Intervention (See Chap. 11)

A consensus conceptual definition of self- management interventions has recently been agreed upon to clarify what should be considered under the heading of a self-management intervention [22]: "A COPD self-management intervention is structured but personalised and often multi-component, with goals of motivating, engaging and supporting the patients to positively adapt their health behaviour(s) and develop skills to better manage their disease."

The ultimate goals of self-management are (a) optimizing and preserving physical health; (b) reducing symptoms and functional impairments in daily life and increasing emotional well-being, social well-being, and HRQoL; and (c) establishing effective alliances with healthcare professionals, family, friends, and community. The process requires iterative interactions between patients and healthcare professionals who are competent in delivering self-management interventions. These patient-centered interactions focus on (1) identifying needs, health beliefs, and enhancing intrinsic motivations; (2) eliciting personalized goals; (3) formulating appropriate strategies (e.g., exacerbation management) to achieve these goals; and if required (4) evaluating and readjusting strategies. Behavior change techniques are used to elicit patient motivation, confidence, and competence. Literacy sensitive approaches are used to enhance comprehensibility.

Health Behavior Changes

There is a multiplicity of behaviors, which the patient has to adapt in chronic respiratory disease; those could vary over time and with the disease trajectory. Table 1.2 presents changes in health behaviors and skills that may be needed in chronic respiratory disease such as taking medications, preventing or minimizing negative side effects, monitoring symptoms, recognizing acute episodes and making decision for prompt treatment adjustment, controlling dyspnea, and adopting and maintaining healthy lifestyle (avoidance such as being in smoke-free environment and keeping home allergy-free, exercise and/or being physically active). The approach has to be personalized; it is fundamental that self-management behavior modification interventions are based on the patient needs and capacities within the environment of a supportive healthcare system. For some patients, it may be aiming at smoking cessation, for other patients managing dyspnea in activity of daily living or exacerbations, but always taking into consideration the patient's own preferences, needs, and personal goals.

This being said, we cannot design a new intervention for each individual, but we can take standardized self-management components and tailor them to better fit every patient. The patient's ultimate goal needs to be defined as their desired achievements in work, home, and/or leisure. The physician, and in more complex cases, the case manager will act as a health coach to guide the patient in defining and reaching their goal(s). This has been the foundation of self-management programs such as the Living Well with COPD, … with Lung Fibrosis and … with Severe Asthma. The program allows modification with continued emphasis on self-management but is also informed by the need to integrate behavior modification and motivational interviewing skills to achieve optimal self-management. It is important to remember that not only the patient's motivation, confidence, and skills but also

Table 1.2 Healthy behaviors and skills that may be required for patients with chronic respiratory disease

Specific behavior	Self-management skill (strategy)
Live in a smoke-free environment Live in a home allergy free Comply with your medication	Quit smoking, remain nonsmoker, and avoid secondhand smoke Allergy control begins at home with controlling the contact with indoor airborne allergens Take medication as prescribed on a regular basis and use proper inhalation techniques
Manage to maintain comfortable breathing	Use according to directives: 1. The pursed-lip breathing technique 2. The forward body position
Conserve your energy Manage your stress and anxiety	Prioritize your activities, plan your schedule, and pace yourself Use your relaxation and breathing techniques, try to solve one problem at a time, talk about your problems and do not hesitate to ask for help, and maintain a positive attitude
Prevent and seek early treatment of exacerbations	Get your flu shot every year and your vaccine for pneumonia Identify and avoid factors that can make your symptoms worse Use your plan of action according to the directives (recognition of symptom deterioration and actions to perform) Contact your resource person when needed
Maintain an active lifestyle	Maintain physical activities (activities of daily living, walking, climbing stairs, etc.) Exercise regularly (according to a prescribed home exercise program)
Keep a healthy diet	Maintain a healthy weight, eat food high in protein, and eat smaller meals more often (5–6 meals/day)
Have good sleep habits	Maintain a routine, avoid heavy meals and stimulants, and relax before bedtime
Maintain a satisfying sex life	Use positions that require less energy Share your feelings with your partner Do not limit yourself to intercourse, create a romantic atmosphere Use your breathing, relaxation, and coughing techniques
Get involved in leisure activities	Choose leisure activities that you enjoy Choose environments where your symptoms will not be aggravated Pace yourself through the activities while using your breathing techniques Respect your strengths and limitations

Adapted from Bourbeau and Nault [2]

their needs evolve over time, so the way to deliver the intervention and the timelines are going to be different for different patients. In order for the self-management program to be successful, frequent interactive communication with the patient is needed, especially with those having high disease burden.

During the continuum of disease management, the contents and components of the program will vary to adapt to the situation of the patient and to factors such as disease severity, comorbidities, and access to healthcare (Fig. 1.1) [23]. When patient capacity to self-management decreases and/or severity of illness increase as

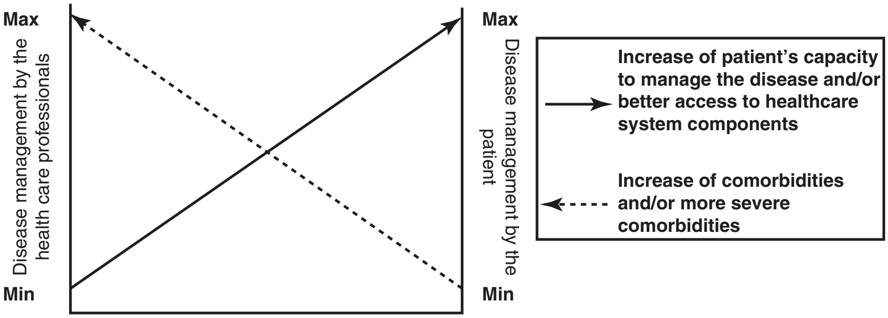

Fig. 1.1 Continuum of disease management. On the continuum of disease management, the components and content of self-management will vary depending on factors such as disease severity or comorbidities. As patient gain confidence, they can engage more on disease management. When the patient management decreases (e.g., severity), management by health professionals will increase [23]

part of the trajectory of the chronic disease, disease management by the healthcare professionals will increase proportionally. This has been demonstrated in a study of a real-life situation that in more severe COPD patients in order to be effective and harmless and to lead to appropriate self-management behaviors, the program must include essential components such as easy access, timely interaction, and increased telephone communications with a highly skilled case manager [8]. Furthermore, the decision will always be guided not only to aim at patient self-management but to ensure patient safety. This can only happen in an integrated system of care well adapted and responsive to patient needs [24].

Patient Engagement, A Precursor to Successful Self-Management Intervention

Information or advice on its own does not promote adherence or lead to changes in behavior. Patients have to become active agents taking charge of their own health and their interaction with health services. With the understanding that patients need to be involved in the management of their health, patient engagement has been recognized as a crucial component of self-management interventions.

Definition of Patient Engagement

There is no universal definition for patient engagement. A systematic review underlines significant heterogeneity among definitions. Patient engagement is often measured by the performance of a set of healthy behaviors [25]. Some have also described engagement as a relational factor, such as quality of patient–healthcare professional interactions [25]. Finally, in some papers, engagement was an organizational feature of healthcare service delivery, encompassing overall quality of care and cost of healthcare services [25]. Therefore, patient engagement may be observed from multiple perspectives, individual, relational, and organizational dimensions; for this chapter, patient engagement refers to the individual perspective, e.g., performance of a set of healthy behaviors.

Patient Engagement Process

Engaging in appropriate self-management behaviors involves a complex series of behavioral changes. Studies suggest that to improve health behaviors and engagement in self-management, interventions should target enhancing intrinsic motivation to change [26, 27].

The patient engagement process starts with effective communication between an individual and his or her healthcare professionals. A productive exchange of ideas and strategies leads to personal accountability and involvement in decision-making that is followed by improvement in clinical care outcomes. The healthcare professional plays a major role in the form of the patient's coach, to give out the guidebook, and the provision of legitimization of self-management. Having a guidebook can be used to raise awareness, to monitor patient's own condition, and to make management changes as necessary. It can give the patient a feeling of control and ownership of information that will be used to support current or future treatment. A good example is the self-management program for COPD patients and families "Living Well with COPD" (www.livingwellwithcopd.com); the patient education process established in this program guides healthcare professionals who play the role of the case manager in assessing patient readiness and motivation to learn, set mutual realistic learning goals and objectives with patient and family, implement individualized or group educational interventions, and evaluate patient outcomes. Furthermore, the healthcare professional is the gateway into making the self-management information both accessible and a source of emotional support.

However, patients are not always motivated to adopt healthier behaviors or engage in recommended disease management strategies—even when there are clear benefits. Motivation is defined as "the activation of goal-oriented behavior." Individuals are said to be intrinsically motivated when they will engage in a behavior without obvious external incentives (e.g., praise, monetary rewards) because it is consistent with their values or life goals [28]. For patients to be able to assume greater responsibility for healthcare decisions and actively engage in behaviors, they need the collaboration of healthcare professionals who act as a case manager or coach. An approach of health coaching increases the chance of being successful when the patients mobilize internal strengths and external resources for sustainable change [29] emphasizing the two types of resources (internal and external) required to be mobilized to achieve benefit, mostly through patient's engagement.

Central to self-management and health coaching programs is motivational interviewing (see Chap. 6) or communication approach, a strategy that incorporates client-centered communication style. The ability of healthcare professionals to engage in effective communication can reinforce or discourage health actions that maximize a patient's capacity to adapt behavior with a chronic condition. To improve health behaviors and engagement in self-management, self-management interventions need to target enhancing intrinsic motivation to change. By using client-centered communication (motivational interview or communication), patients are encouraged to express what intrinsically motivate them (e.g., consistent with their values or life goals) to adopt certain health behavior, with the goal of helping them overcome their ambivalence about change (e.g., "I want to be more physically active, but I always get out of breath"). For change to occur, patients need to feel that change will be both beneficial to them personally and possible.

Motivational communication largely based on motivational interviewing is a client-centered communication style that encourages patients to express what intrinsically motivates them to adopt a certain health behavior, with the goal of helping them overcome their ambivalence about change [27, 30]. For change to occur, patients need to feel that change will be both beneficial to them personally and possible. Motivational communication approaches will help engage patients to take greater responsibility for their health and well-being; physicians and other healthcare professionals will serve as guide in the behavior change process. Motivational communication and interview approaches have been shown to improve rates of smoking cessation, promote physical activity, and improve medication adherence in various chronic diseases [31]. Studies in COPD have shown motivational communication approaches to be effective as part of self-management or health coaching programs [7, 32].

Model to Increase Patient Engagement

Having a model to understand the elements that interact (person, environment, or behavior) may improve our ability to help patients engage. Recently, a model has been suggested, the "Engagement capacity model" [33], based on the known social cognitive theory of Bandura [34, 35]. This theory is useful as it helps us understand how patients initiate or maintain a specific behavior. This framework includes the concept of "reciprocal determinism" [36], the idea being that there is a dynamic relationship between the person, their environment, and their behaviors, in which they continually influence each other and are influenced by each other. The experience patients have learning a new behavior will influence in performing that behavior in the future.

The model proposed encompasses four dimensions that fall within the person–environment–behavior domains: (i) willingness (motivation), (ii) self-efficacy, (iii) resources, and (iv) capabilities (Fig. 1.2).

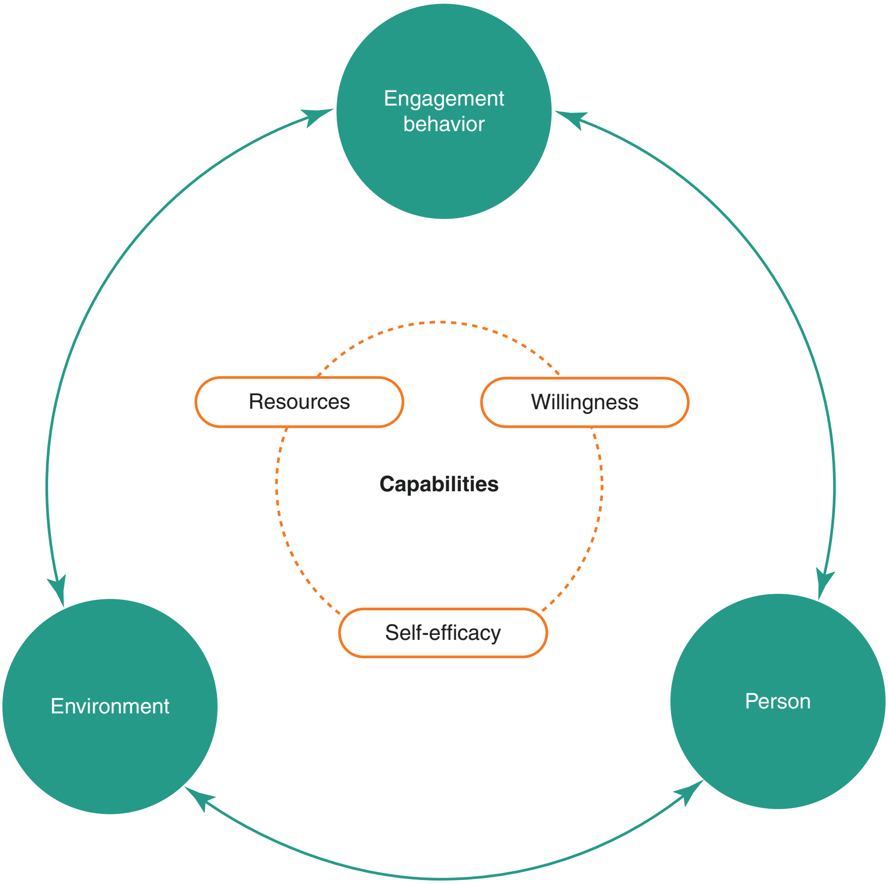

Fig. 1.2 Engagement capacity model [33]

(i) Willingness – Having or showing willingness to work toward achieving goals is the most important element. A patient will find change beneficial if it leads to personally relevant or valued outcomes (intrinsic motivation). Thereafter, a patient has to find that the change to make it possible in his or her ability (self-efficacy).

(ii) Self-efficacy – There is empirical evidence to support the notion that behavioral performance and patient's belief in their ability to perform in varied situations and disease states are linked by self-efficacy. Patients with strong efficacy beliefs are able to withstand failures associated with mastering a complex task and are more likely to persist in their efforts with difficult tasks [36]. Various strategies can be used by the healthcare professional to enhance patient's self-efficacy and can be summarized with the following: (1) practice (2); feedback (3); reattribution of the perceived causes of failure when the patient has negative experiences (4); sharing experience (role model) [37].

Task-specific efficacy beliefs are often initially low and increase as the patient persists and takes experience. Patients who have been successful in the past and who are willing to share their positive experiences with new patients (in a group setting) can provide a strong modelling effect: learning from a peer that succeed in changing the behavior(s) is indeed possible will enhance their own self-efficacy expectations.

(iii) Resources – Factors external to the individual that support participating in care: financial resources; access-related resources (internet access to online patient materials, transportation); and person-related resources (e.g., having a case manager with good communication). Patients with fewer resources would be less likely to fully engage in their health care.

(iv) Capabilities – Behavior initiation and/or maintaining implies the individual's "capabilities" or the skills that enable them to perform a behavior. Table 1.2 present the many changes in health behaviors and skills that may be needed for a patient with a chronic respiratory disease.

This framework has the potential to help healthcare professionals and healthcare organizations identifying the dimension(s) of engagement that create the greatest barriers for individual patients and/or their patient population as a whole, and allocate their resources accordingly.

Engaging Patients to Better Understand and/or Make Decisions

Shared decision-making, "an approach where clinicians and patients share the best available evidence when faced with the task of making decisions, and where patients are supported to consider options, to achieve informed preferences," is one of the elements commonly considered important in patient-centered care, a good standard to improve the quality of chronic disease care. Patients who participate in their decisions report higher levels of satisfaction with their care; have increased knowledge about condition, tests, and treatment; have more realistic expectations about benefits and harms; are more likely to adhere to treatment plans; have reduced anxiety; and may have improved health outcomes [38, 39]. Shared decision-making should be part of any intervention aiming at behavior change such as self-management; building a good relationship so that information is shared and patients are supported to express their preferences and views during the decision-making process.

However, care decisions should also be based on best practice guidelines and quality control processes. COPD self-management programs for patients and families should include interventions and/or behavior changes that have proven scientific validity if we want to expect improvements in health outcomes such as patient's risk of exacerbation, symptom relief, health status, and health service use. In the self-management model, case managers are used as health coaches to empower patients with knowledge and confidence to take over the responsibility of managing the illness.

Conclusion

The crux and burden of chronic disease management and health behavior change both must be done by the patient. Many healthcare decisions have a trade-off of potential benefits and harms, and sometimes there is close balance of benefit to harm. Favorable outcomes can only happen in an integrated system of care well adapted and responsive to patient needs, and by including patient values and preferences.

There is growing literature on how patient engagement and self-management impact the experience and improve outcomes. Better engagement increases the perception of personal control, increases trust, and decrease uncertainty. Clinician communication styles are critically important to effective patient engagement, and good communication creates a sense of partnership.

Interventions aimed at supporting behavior change, such as self-management, share principles of health coaching with iterative interactions between patients and healthcare professional (case manager) with the goals of motivating, engaging, and supporting the patients to better manage their disease and adopt healthy behaviors. The process should be patient-centered aiming at achieving self-determined goals, e.g., self-management toward the goal or goals patient has set.

Finally, a framework has recently been proposed, the "Engagement Capacity Model", to help focus efforts by enabling physicians and healthcare organizations to better classify a patient's capacity for engagement through assessment of their self-efficacy, willingness, resources, and capabilities. This framework will need to be validated and to be assessed in real-world research.

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Chapter 2
Learning: Developing Knowledge Through Making Meaning

Zachary Fulkerson, Geoffrey Norman, and William G. Carlos

Introduction

Education of the patient has been a cornerstone of medicine for centuries. Early generations of healthcare professionals could offer patients little beyond prognostication, explanations for reasons for illness, and attempts at helping the patient derive meaning. As the general public has become more educated and medical care has become more complicated, the need for patient education has increased. Indeed, the necessity for patient education is implied by the core biomedical principle of autonomy as an individual's self-determination is not possible without access to information. The need for a better-informed patient population became more explicitly defined in the twentieth century. As early as 1914, the notion of informed consent was articulated by Justice Benjamin Cardoza:

> Every human being of adult years and sound mind has a right to determine what shall be done with his own body; and a surgeon who performs an operation without his patient's consent commits an assault for which he is liable in damages. This is true except in cases of emergency where the patient is unconscious and where it is necessary to operate before consent can be obtained. [1]

Later in the twentieth century, consent alone was not considered sufficient. Rather, *informed* consent in which a patient was educated on consequences of particular therapeutic interventions became more strictly enforced. By the 1970s, the need for general education beyond informed consent processes was codified. In 1973, the American Hospital Associated published *A Patient's Bill of Rights,*

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articulating the right to information regarding diagnosis, treatment, and prognosis. Such bills of rights have been subsequently adopted by different organizations and state legislatures [2].

Beyond the ethical implications regarding the rights of patients to healthcare information, there are important cultural and moral changes that are worth considering. Medicine is becoming less and less paternalistic. We increasingly recognize that healthcare occurs outside the clinic and hospital and that it inevitably requires partnerships with patients and families. We begin patient encounters with asking them to educate us – on what their symptoms are, how these symptoms affect their lives, and what their concerns are. We end patient encounters by summarizing the patient's problems and then educating the patient on the importance and timing of ongoing diagnostic tests and treatments. In this chapter, we will outline the principles and theories of adult learning for the purpose of improving patient education.

Learning Theories

Over the course of the nineteenth through twenty-first centuries, there have been a number of collections of theories to attempt to explain how children and adults learn. While none of these is comprehensive, they all shine a slightly different light on the learner and can each provide insights into strategies that assist with patient education. The strategies we will focus on include:

- *Behaviorism* with a focus on external responses to stimuli rather than internal cognitive processes themselves.
- *Cognitivism* which focuses on internal processes to organize and interpret stimuli.
- *Constructivism* which focuses on the ability of the learner to learn through created experiences.
- *Connectivism,* a recent theory that attempts to explain the different modalities and network methods by which a person acquires information.

Behaviorism

In the late nineteenth and early twentieth centuries, the theory of *behaviorism* was developed. The focus of this theory was on the concrete and observable. Since cognitive processes themselves are not observable, these processes were not considered in regard to development of most theories and largely existed in a black box (Fig. 2.1). The main emphasis was the *response* an organism had to a particular *stimulus.* Learning was seen as the connections that people (or animals) made between stimuli and responses.

In the late nineteenth century, a series of experiments conducted by Ivan Pavlov (1849–1936) developed the basis for *respondent conditioning* (*classical conditioning*) by demonstrating the role of combining stimuli to elicit a response. Pavlov first

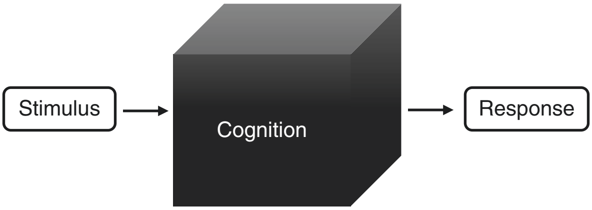

Fig. 2.1 Behaviorists focused on externally observable components of learning. Therefore, much of the interest was placed on a subject's response to a stimulus. Since cognitive processes are not directly observable, the human mind was essentially a black box and not necessary for developing theories of behaviorism

noted that some stimuli were innate (unconditioned). The smell of food (stimulus), for example, innately caused a dog to salivate (response). By definition, this unconditioned response did not need to be learned but occurred naturally. His insight was that by combining this innate stimulus (food) with a neutral stimulus (ringing a bell), these stimuli could become associated so closely that the ringing of a bell could induce salivation. In this way, the dog learned (or was conditioned) to respond to the neutral stimulus. Importantly, these connections could be extinguished if the neutral stimulus occurred enough by itself (e.g., if the bell rang without the appearance of food) [3].

Classical conditioning focuses primarily on stimuli that occur *prior* to a response. However, the later behaviorist B.F. Skinner (1904–1990) described the role of stimuli that *followed* a response. In *operant conditioning*, he characterized the role of reinforcements or punishments following a response. Examples of positive reinforcers include grades, praise, and money. The association between the reinforcement or punishment and the desired behavior are modified by a multitude of factors including the type of reinforcement (or punishment), the reinforcement schedule, the specificity of the reinforcement for the particular behavior, and the immediacy with which the reinforcement occurs. Immediacy and specificity likely play a role in solidifying causality of the reward with the stimulus. For example, slot machines are made more addictive when reinforcements occur immediately after a "pull" as opposed to when the reinforcement is delayed [4]. Likewise, a person developing sneezing, rhinorrhea, and hives *immediately* after exposure to a cat and *only* after exposure to a cat will likely begin to draw causal relationships (even if it is not at a conscious level).

Applications

Behaviorist principles themselves do knowingly or unknowingly affect healthcare professional interactions with patients. For example, praise may be given to a patient who has quit smoking (positive reinforcer) while lack of response (nonreinforcement) or disapproving look (punishment) may be given to a patient who continues to smoke. A particular limitation to behaviorism in general is that the subject is considered to be passive and lacking free will. In this model, learned behaviors are nothing more than responses to stimuli with the subject having very little control of those responses. This is clearly at odds with our notion of patients as unique individuals with agency. If learners are viewed as being relatively passive, ethical concerns come to the forefront such as who is actually deciding on the desired behavior – the healthcare professional or the patient? Consequently, strict behaviorism may be contrary to the notion of patient autonomy and building a therapeutic partnership.

Even if strict behaviorist principles are not utilized in the clinic setting, it is important to note the role of these principles in the everyday world. This is especially true as it relates to smoking abuse and other addictions. Operant conditioning is primarily at play as the nicotine in cigarettes (similar to other drugs of abuse) converge on a dopaminergic reward pathway in the limbic system providing a positive reinforcement [5]. As cigarettes themselves are a very rapid delivery device achieving detectable blood levels of nicotine in seconds to minutes [6], there exists a strong relationship between behavior and reinforcer. This behavior is further strengthened by withdrawal effects when smoking stops. Indeed, the mechanism of action for varenicline (Chantix®) is that of a partial agonist of certain nicotinic receptors. From a behaviorist perspective, varenicline minimizes the reinforcement achieved from smoking a cigarette while mitigating withdrawal symptoms (i.e., minimizing the punishment associated with smoking cessation) [7].

Beyond this strict operant reward system that works to maintain smoking, patients also develop strong triggers. Many reports have demonstrated that people can develop urges and physiologic responses to neutral stimuli when paired with smoking demonstrating that environmental cues can be classically conditioned to smoking [8]. Furthermore, classical conditioning strategies have historically been used in advertising campaigns for cigarettes to associate smoking with social acceptance, sexual appeal, etc. In later years, public service announcements have attempted to associate cigarettes (neutral stimulus) with more negative stimuli. As an example, the *Tips From Former Smokers®* campaign from the Centers for Disease Control and Prevention (CDC) makes efforts to connect cigarette smoke viscerally with unwanted consequences that may occur [9].

Cognitive Psychology

While behaviorism is useful for understanding simple responses to a small number of stimuli, the theory is inherently limited. There is no insight into the "black box" of cognition. Furthermore, predictable responses to stimuli are not always observed. Words of praise given to one patient may be a positive reinforcer though may seem patronizing to another and thus have the opposite effect. Finally, behaviorism has a fundamental limitation; it provides no explanation for people's ability to generalize, use analogy, or problem-solve. *Cognitive Psychology* attempts to address some of limitations of behaviorism and place more focus on the learner rather than the environment. Developed in the mid-1950s, it metaphorically drew parallels with computing systems emphasizing how information is received, processed, organized, and retrieved. However, as research findings accrued, the contrast between human brain architecture and computer architecture has become more apparent.

The Architecture of the Mind

Following the computer metaphor, the mind is generally described with specific modules [10]. People interface with and receive information from the external world through senses (e.g., vision and hearing). Precisely how this information is extracted from the environment is explored through studies of "attention and perception." A central notion of attention and perception is the concept of *working memory* which is somewhat analogous to the random-access memory (RAM) of a computer. However, unlike computer RAM, which has expanded exponentially as computers get more and more powerful, human working memory is severely restricted – approximately seven "chunks" of information [11]. Finally, the processing that occurs in working memory involves accessing prior knowledge in "long-term memory."

The Sensors: Attention and Perception

Due to the constraints of working memory, there are inevitably more stimuli than any person can attend at a single time. As such, learning new information requires selective attention to particular stimuli. These stimuli are not always the same between patient and healthcare professional. The pertinent details of a patient room or hospital room may fade so far into the background for the clinician that it does not register in the conscious mind, whereas these details may be the first and most important impression the patient has about the clinical encounter.

With recent developments in technology such as the omnipresence of computers and smartphones, people (patients and healthcare professionals alike) often believe they have increased their ability to *multitask* (i.e., attend to more stimuli than was previously possible). While this liberation from the constraints mind architecture is popular, careful study shows that the only way a person can "multitask" is when one of the tasks is completely automatized (e.g., driving on a quiet street and carrying on a conversation) [12]. Instead of multitasking, people are more prone to task switching, a practice that comes at the expensive of attentiveness.

In the medical profession, it is particularly important to bear in mind physical and mental limitations that may impede perception such as hearing and visual impairment, cognitive decline, and hemineglect. Even in the absence of deficits, people are capable of only attending to a finite number of stimuli. Therefore, if a patient is worried about a hospital bill, catching a bus home, or a chronic symptom, he or she may be unable to attend to patient education regardless of how well it is presented. Acute illness may further compound patients' ability to attend to information. Pain, medications, sleep deprivation, and delirium may all impede with a patient's ability to pay attention and thus make learning more complicated and daunting. Naturally, patients are not the only people with various stimuli that compete for attention. Indeed, this happens for healthcare professionals on a daily basis. Concerns regarding clinical workload, an upcoming difficult conversation, a grant deadline, or personal problems may all interfere with our ability to perceive and understand concerns from the patient. It is therefore important to be cognoscente that healthcare professionals and patients may be attending to, and interpreting, very different stimuli during an encounter.

Working Memory

One of the most critical elements of memory, in terms of capacity to learn new information, is working memory. Working memory is the component of the mind where active intentional processing takes place and where information is passed from the external world to long-term memory (i.e., learning). As stated above, working memory is limited to about seven bits of information. This is notable in everyday experience; many people begin having difficulty remembering numbers after about seven digits. Methods of overcoming this limitation include combining information (or numbers) into "chunks" (e.g., remembering an area code as a single bit of information) or by using associations with previously learned paradigms to facilitate meaningfully encoding information into long-term memory [13].

Experts in some domains like chess extend their memory prodigiously through this strategy. One study from the 1970s assessed the ability of chess masters to remember the positions of chess pieces in a mid-game position after reviewing the chessboard for only 5 seconds. A chess master could correctly recall the position of about 85% of pieces on the board compared with only 5% for a novice. The master's advantage over the novice completely vanished when a similar number of pieces were placed on the board *randomly* – indeed the chess master did worse than the novice [14]. The explanation for this peculiar finding is that the chess master, who had spent years learning, had a different mental map for understanding a chessboard. While viewing a game in progress, the chess master was able to view the board not as individual pieces but as a smaller number of "chunks" that fit into a mental model built upon years of experience. The chess master's working memory was not improved in the slightest, which is why previous chess experience provided no benefit when the pieces were positioned randomly. Rather than having a meaningful way of encoding information into long-term memory, the chess master (like the novice) was completely reliant on the very limited working memory.

Human Associative Long-Term Memory (HAM)

The above scenario highlights one of the ways people are able to meaningfully encode information into long-term memory – namely by association. As an example, memorizing a line of poetry in one's native language would be relatively simple, whereas memorizing an equally long line of poetry in an unfamiliar language would be daunting. Likewise, memorizing a few measures from a piece of music would be dramatically easier for a professional musician compared with a person who has never studied music before. This is one of the main reasons that the human mind differs from a computer. Interestingly, human associative long-term memory has essentially infinite capacity (as it is always able to assimilate and accommodate new information) and has an amazingly rapid processing time of a fraction of a second. Solving a problem or learning something new is all about associating the new information with information already in memory. Arguably, most of human learning amounts to building new information on top of what is already known. As stated by Robert Bjork et al:

> *….. we do not store information in our long-term memories by making any kind of literal recording of that information, but, instead, we do so by relating new information to what we already know. We store new information in terms of its meaning to us, as defined by its relationships and semantic associations to information that already exists in our memories.* [15]

This model of memory has significant implications for learning. Essentially, we must use multiple strategies to help patients relate what we are telling them to what they already know. Strategies include use of analogy, making explicit linkages with what they know, helping them to actively learn through questioning, distributing the learning material over multiple spaced sessions, and many other strategies [16].

Applications

The implications of these insights to patient education loom large. There is some evidence that the size of working memory correlated to Intellectual Quotient (IQ) [17]; however, regardless of intelligence, working memory is *dramatically limited* (again to about seven bits of information). When people have multiple superfluous stimuli that are diverting attention, learning is hampered. Indeed, there is no worse example of this clutter than the nightly television news with different information emerging all over the screen. These additions have repeatedly been shown to have a *negative* impact on learning [18]. The basic idea has been captured in a theory of learning called "cognitive load" theory [19], which hypothesizes that effectiveness of learning is negatively related to the amount of cognitive load the material imposes on working memory. This is why speaking in simple sentences, using plain (non-medical) language, in a setting that is free from distractions is critically important. The goal of effective instruction is to maximize relevant load and minimize extraneous load. In other words, keeping it simple.

Beyond recognizing the limitations of working memory, it is also important to bear in mind the ways that people move working memory into long-term memory – by creating associations with previously learned material. Very often, we as healthcare professionals have a sense that we possess all of the relevant knowledge and simply need to impart this knowledge upon our patients and their families. We fail to recognize that our own unique experiences shape the way we understand the world, and the same is true for our patients. Going back to the previous example, chess masters interpret a chessboard differently than other people because of years of experience, which results in chess masters creating unique mental models they use to create meaningful associations. Likewise, healthcare professionals have years of creating mental models that differ from patients. This means that healthcare professionals and patients may remember, interpret, and understand new information very differently.

During a session with a patient or family, it is critically important to have frequent "check-ins" in order to ensure that (1) the patients' understanding is consistent with what we are trying to convey and (2) our own mental representations are in accord with the patients' concerns. Nowhere is this truer than during complicated decisions regarding treatments with high morbidity. Queries like "What do you mean by never wanting to live on a machine?" or "Tell me more about what you mean by doing 'everything'" are crucial for ensuring that *meaning* gets conveyed accurately.

Constructivism

Developed in the late twentieth century, *constructivism* focuses on the ability of the learner to engage with his or her environment, reflecting on their experience, and then creating meaning from that experience. There are many parallels with the development of different schemas (mental framework), which cognitivists describe. A move toward this type of learning has been seen in traditional undergraduate medical education with the increasing utilization of problem-based learning.

While there is limited evidence regarding efficacy, there are problem-based programs for patients. For example, group learning sessions in management of diabetes may focus on patients "experimenting" with creating meals and determining their insulin coverage. A trial of a problem-based learning curriculum for patients after a coronary event is currently underway where investigators are attempting to assess changes with self-efficacy and empowerment [20].

In a very practical sense, patients often have a wealth of information which they provide. For example, which rehabilitation facilities help them best achieve their functional goals, which inhaled delivery device is the easiest to use, and side effect profiles of a host of medications. Many healthcare professionals would never know these nuances without intentionally interacting with patients' prior experiences. Acknowledging these insights can assist with empowering the development of a therapeutic relationship between healthcare professional and patient.

Connectivism

Just as many of the cognitivist notions of information processing occurred in the mid-twentieth century with the development of modern computing devices, *connectivism* began to take route as computing devices became more interconnected

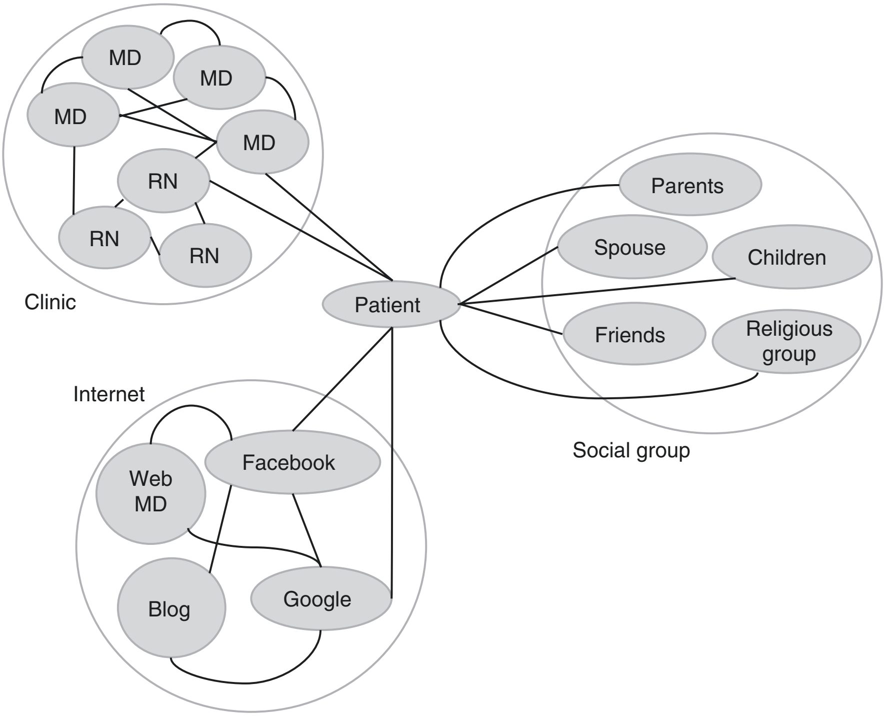

Fig. 2.2 Demonstration of connectivism. Patients may have a multitude of sources for information for which the patient may also contribute. These form a series of nodes and connections that can form a vast network

through web media, communication applications, and social media. Many patients explore opinions outside of the clinic through vast networks of connections (Fig. 2.2). While these outside sources had historically been close social contacts such as family and friends, they have been exponentially expanded by the near-universality of the Internet and social media.

Support groups have expanded to not just include local support groups, but international support groups. In the realm of pulmonary and critical care, there are online support groups for chronic obstructive pulmonary disease (COPD), cystic fibrosis (CF), idiopathic pulmonary fibrosis (IPF), and critical care survivorship—just to name a few [21–24]. Benefits of such support groups include emotional and informational support, as well as companionship being able to relate to people with shared experiences [25]. Many of these benefits are simply not possible in the confines of a strict patient–healthcare professional relationship.

While there is a clear benefit to the abundance of interactions and information, there is also a clear downside. There are potential harms such as emotional turmoil from increased vulnerability in an online setting. Misinformation is another potential harm with anti-vaccination content being the most prominent example.

Applications

In the future, the interaction of patients with online content and support groups is likely only to increase. It will be increasingly important for healthcare professionals to be aware of such social groups and content and to be inquisitive. Helping patients navigate this ever-growing space is likely to become increasingly important. Likewise, staying informed and connected with these platforms ourselves will be crucial.

Conclusions

Patients need to know why they have a diagnosis and what to do about it. Education is a critical element of patient care. Much has been written about best practices in learning and much has yet to be written. There are a number of learning theories that have been put forward to assist with understanding how people learn. While none of them are by any means comprehensive, they help shed light onto how our patients (as well as ourselves) make meaning of the world and their health. In most of our clinical practices, we apply a multitude of theories with or without realizing it. Our sincere congratulations to a patient after quitting smoking stems from behaviorist roots – not that we are trying to manipulate a patient's behavior but rather trying to reinforce a mutually agreed-upon plan. Asking patients "Tell me in your own words what your understanding of your illness is" highlights cognitivist principles. It acknowledges that we view new information through the prism of our past experiences, which colors our understanding. Finally, inquiring about outside resources and even inviting patients to join a support group (in person or online) acknowledges the network of information in which patients participate – a network that extends far beyond the confines of the clinic.

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Chapter 3
Psychomotor Skill Development: Learning What and How To Do

Felicity Blackstock and Shane Pritchard

Humans interact with their world through movement, either by moving through the environment, handling objects, or through social interactions with other people, such as talking and hugging. In order to do this, we need to simultaneously, and in sequence, control a significant number of different movements that vary in complexity and speed. We must also consider and deal with multiple, usually inter-related, sensory inputs including visual, touch and auditory cues. Essentially, movement is a complex cognitive and physical process that requires a patient to learn how to 'do it'. This chapter explores the theories and principles behind learning new skills such as taking a new inhaler. The concepts presented are foundational to adherence with respiratory healthcare where there is a skill that is needed to adhere to a healthcare intervention. Without the ability to physically complete a task, a patient will never be adherent in an accurate manner that positively impacts on health outcomes.

Definitions and Introductory Concepts

A range of terms are used to describe the components of this concept of motor control, and it is important to appreciate the differences. For the purpose of this chapter, motor control is defined as the processes that underlie the control of movement, skill

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acquisition, and retention of successful movement patterns. Skills are actions or tasks that aim to achieve a specific goal, have a voluntary component, and are learnt. Movements can be referred to as voluntary or involuntary, where reflexes are always involuntary. Motor control can be considered purposeful movements that are voluntarily initiated.

Motor development is the process of change in movement capabilities that a person passes through as they mature. For example, starting from birth, a baby successfully develops from being able to lift their head up, roll onto their side, then sit independently, followed by crawling, and eventually walking. This is in contrast to motor learning, which refers to the change in a person's capability to perform a psychomotor skill following a specific interaction with the environment that is beyond simple maturation. Motor learning is distinct from motor development, as there is a period of instruction, practice, repetition of successful movement, and development of expertise in the movement. Motor development is a more natural change that occurs over time as a person matures. Motor learning is also distinct from performance, as performance is observable; you can see the successful completion of a task. In contrast, learning is not observed but is inferred from the nature of the movement produced during a learning opportunity. The distinction between learning and development is particularly important for paediatric respiratory care, as the stage of motor development of the child needs to be considered when supporting the patient in motor learning.

The skills that develop from learning a new movement are referred to as psychomotor skills. This definition reflects the combination of cognitive processes (psycho-) and movement (-motor) that lead to achieving a goal, such as successful dispensing respiratory medications using an inhaled dry powder available in capsule form. Psychomotor skills can be classified in many ways, and an in-depth exploration of the different classifications is beyond the scope of this chapter. Although, one classification of importance in understanding learning psychomotor skills is whether the muscular involvement requires gross motor or fine motor skills. Gross motor skills refer to movements that involve large muscle groups, such as transferring from sitting to standing, or walking. Fine motor skills involve more precise movements, such as writing, or in the context of chronic respiratory conditions, learning to use an inhaler. Gross and fine motor skills are frequently performed in combination. For example, while you are reading this textbook you are using gross motor skills to maintain posture, and fine motor skills to manipulate the pages of print, or scroll through the pages using a mouse, tablet or screen. Generally, fine motor skills are more complex than gross motor skills, as these require more extensive motor control, with large muscle groups and small muscle groups synergistically working together to achieve the movement task goal.

Learning a Psychomotor Skill: The 'Right Kind of Practice' of a Skill Makes Perfect, Not Just Any Practice

Motor learning requires completing a set of interrelated processes that lead to the relatively permanent changes in capability to complete a specific task that is acquired with practice or as a result of experience [30]. It is a set of internal processes that are associated with lived experiences, which may or may not be formally structured for the purpose of learning the skill [4]. Motor learning involves the active searching of, and subsequent adaption of, many movement patterns to solve a movement problem. Such task solutions are new strategies for acting, which emerge due to constraints imposed by the individual, task, and environment [19]. A person will transition over time from novice to expert, as they refine the movement solution to be as efficient as possible. A novice is observed to have a far higher physical and mental effort as they attempt to complete the task and deliver the movement solution to the problem. The final achievement of successful motor learning is the performance of the task with consistent accuracy.

The successful attainment of a psychomotor skill is not determined by the number of hours of practice. It is a combination of the amount of practice and how the practice environment is manipulated. Manipulation of the environment needs to be based on the complexity of the skill being learnt and the skill level of the performer. The environment needs to facilitate movement and break the movement into achievable stages for the novice so as not to overwhelm. This is needed to facilitate performance of successful movement patterns that are repeated for long-term memory storage. It is important to remember that ultimately the new task is not entirely a new skill, but a new pattern of movement that is rescaling an older task to fit the new goal and environment. Therefore, the principles of learning in a rehabilitation situation are the same as for learning a new task in a state of health [20]. Considering the learning of taking a dry powder capsule inhaler, the environment needs to reflect the environment that the task will be completed. If a patient is to be seated at a table when taking the medication, they should learn in a sitting position at a table. If the lighting will be poor as taken at night, then lighting should be low. The environment is changed to facilitating learning in the environment the task will be completed. The clinician could also begin the task with bright lights to ensure the task is completed correctly, then practiced in a lower light.

Theories of Motor Learning

There are multiple motor learning theories that attempt to explain the phenomenon of learning a psychomotor skill. A summary of what we consider to be the key theories relevant for health professionals are provided in Table 3.1. More recent theories have evolved from older theories, and overlap can be seen between the theories. These more modern theories underpin the current motor learning principles of centring on the interaction between learner, the goals of the task and the features of the environment for supporting successful attainment of the new skill.

Stages of Motor Learning: Cognitive, Associative, Autonomous

As a person transitions from being a novice at a particular psychomotor skill to an expert, they can be said to progress through three stages [8]. The first stage, referred to as the *cognitive* stage, involves the learner focussing on the demands of the task and understanding what is involved. The second stage, referred to as the *associative*

Table 3.1 Summary of the theories of motor learning

Theory	Author (Year)	Description
Closed-loop theory	Adams (1971) [1]	Memory plays an active role, as stored movement memory is used in attempting to complete the task, and feedback from the sensory input guides transformation of that movement to be successful. Memory then recodes and stores the new movement pattern for future application.
Schema theory	Schmidt (1975) [24]	The concept of a generalised motor program underpins the schema theory, whereby a stored motor program in memory does not contain the specifics of a movement, but rather generalised instructions for a given class of movements. That is, motor learning programs exist in the central nervous system, but in a generalised version, within a schema. When moving, the memory of the generalised movement patterns is recalled for application, but are not specific step-by-step memories. This theory then accounts for the variations with which an action can be performed. Sensory input, using integral environmental cues, is still integral, but the memory system is less rigid in the storage and retrieval of information for completion of the movement.
Dynamical systems theory	Kamm et al. (1991) [9], Perry (1998) [22], Vereijken et al. (1992) [31]	The central nervous system has a minimal role in learning to control movement, instead, the role of the goal and that adapted synergies or coordinated structures to achieve the movement goal are emphasised.
Ecological theory	Turvey et al. (1982) [29]	When a performer undertakes an action, physical and environmental conditions change and require subsequent changes to an established pattern of neural signals for the completion of the action. No movement is performed in a stereotypical manner, and thus a central control of all movement is not a feature of this theory. This allows for contextual variability, with the context of the situation driving the selection of neural signals and movement patterns. The learner is seen as exploring their environment, which allows multiple ways for the performance of the task.
Constraints theory	Newell (1986) [18]	The process of motor learning is concerned with discovering optimal solutions through practice that are in line with the performer's own capability, the type of task, and the environmental context. The three main constraints that interact during performance of a coordinated movement are (i) organismic (resources the learner has available to them), (ii) task (the rules of successful completion of the movement) and (iii) environmental (the context of the movement). The interaction between the three constraints governs coordination and the ultimate movement pattern observed.

stage, involves the learner becoming more concerned with producing an efficient and refined movement. The third and final stage, being the *autonomous* stage, is characterised by the skills becoming 'automatic', and where the learner can focus on other aspects of their environment while still competently completing the task.

If we consider use of a dry powder inhaler with capsule as the psychomotor skill, the cognitive stage would involve understanding how the inhaler works; the associative stage would involve learning to dispense and inhale the medication as effectively and efficiently as possible; the autonomous stage would involve the learner considering when to take the inhaler relative to symptoms and other medications, and being able to apply the inhaler in a range of different environments, such as during an exacerbation as well as when stable, without a reduction in overall effectiveness or efficiency.

In the cognitive stage, the learner needs to concentrate intensively, attending to many, if not all, aspects of the task. Novices might be observed to make several mistakes and move in a manner that was not necessarily achieving the goal of the task or looked slow or jerky. In this stage, the learner is concerned with understanding the task and might ask many questions. Learners attend to many different cues, events and responses that will go unnoticed once the learner moves to the future stages. For example, in using a dry powder inhaler with capsule, a novice learner will concentrate on their hand position in holding the inhaler, and focus on how to open the lid, crack the capsule out of the packaging and then precisely insert the capsule into the plastic case for inhalation. In future stages, this concentration will decline as the movement becomes more automatic. Instructions and demonstrations are useful to support learning for a person in the early cognitive stage, as the learner acquires the knowledge and ‘psycho’ component of the psychomotor skill development. The use of manual guidance of movement and facilitation is often required to show the patient how to move. Occasionally, a learner will engage in self-talk during the cognitive stage [25], verbally guiding themselves through completing the task. Little consistency is observed in performance of the movement at this stage; however, improvements in performance are quite large and occur frequently.

The associative stage is characterised by a level of success in completing the task, as the learner begins to take additional cues from the environment such as the time it takes to inhale when taking their medications using a dry powder inhaler with capsule. The patient begins to be able to detect errors and problem-solve the solutions in order to achieve the desired outcome without the therapist being required to provide explicit feedback. This second stage of learning can span a varied period, depending on the complexity of the task [8] and prior experience and transferrable skills of the learner. A learner will begin to discover cues for effective timing of the action and anticipatory skills dramatically improve, making movements smoother and better timed. Fewer errors are therefore made, but some intersession variability is still apparent as the learner experiments to find new solutions to any problems encountered. This enhanced movement efficiency then reduces energy costs, and self-talk is observed to become less important.

The final autonomous stage is when the skill is seen as automatic, habitual, and completed without significant intentional direction. The movements require less cognitive control and are subjected to less interference from ongoing activities and the environmental distractions. In this stage, the learner will assess their speed, efficiency and accuracy of completing the task, which will also then continue to improve. Variability in performance will decrease to become very low, with the skill performed consistently from one session to the next. A learner will also be able to detect their own errors and self-correct them independently and quickly. The likelihood of the learner reaching this final stage is heavily dependent on the quality of the instruction and practice they have completed.

The Role of Memory in Psychomotor Skill Development

Memory plays an important role in our daily activities, as we remember facts such as numbers, names and locations. We are also able to remember procedures, such as how to boil an egg for breakfast. Similarly, memory also plays a role in remembering sequences of movements for psychomotor skills. Fascinatingly, after development of a psychomotor skill is complete, the ability to complete the task can be stored for decades. For example, if you learn to ride a bike as a child, not ride the bike during your early adult years, and then get back on that bike today, you can still ride successfully. Interestingly though, we are more likely to be able to remember continuous psychomotor skills (such as bike riding) than discrete skills (such as sewing), and it is considered to be related to discrete skills having a higher verbal-cognitive component than continuous skills [26]. To be able to recall a skill decades later, both short- and long-term memory are needed during learning a psychomotor skill.

Short-term memory in psychomotor skill development is required before information is transferred to long-term memory. Short-term memory is sometimes also referred to as working memory, as the information that is attended to during completion of a movement task (working information) is first stored in short-term sensory before being moved to long-term memory. Therefore, it is important for a learner to pay attention to specifics related to completion of the task. If attention is not directed to the key specifics of the movement, short-term memory storage does not occur, and the transfer to long-term memory subsequently also does not occur. For example, attention needs to be drawn to the angle of the inhaler in the patients mouth and the depth of insertion into the mouth, such that the proprioceptive joint angles information is then stored in short-term memory, so that the correct angle of inhaler for insertion can be remembered longer term. The repetition of the task, and repetition of attention to the specifics of the successful movement, then passes the rehearsed information to the long-term memory for application at a future time.

When learning a psychomotor skill, short-term memory cannot be solely relied on as there are two key characteristics that limit the ability of the patient to carry the task on accurately beyond the immediate lesson:

- A very limited capacity: only approximately 7 digits/words can be remembered at once [6, 21]
- Fragility of storage: any distractions usually cause forgetting

Short-term memory can be improved with ‘chunking’ the information into shorter segments while learning. For example, inhaler steps can be segmented into the stage of preparing inhaler, extracting the capsule from the foil wrapping, inserting the capsule into the plastic inhaler, inserting the inhaler into the mouth after exhalation, inhaling, repeating inhalation, and then finally removing the inhaler and packing the inhaler away. Rather than 20 individual steps, there are seven core aspects to remember.

Rehearsal, being practice before needing to perform the task accurately, is imperative to achieving transfer to longer-term memory, and ongoing successful capability development of psychomotor skills. Recency of rehearsal and practice is important, as the information is still active in short-term memory. This has important implications for learning a psychomotor skill, as rehearsal must occur before the memory is lost from short-term memory. Instructions that are brief, succinct and given when the learner is paying attention are also necessary. In addition, important points should be given early in the instruction or at the end, as the middle is more likely to be forgotten. At the beginning and the end, more attention can be applied, and as such, the information more likely to be stored in short-term memory for transfer to long-term memory.

Long-term memory is our ‘day-to-day memory’ (in contrast to short-term memory that is ‘working memory’) as it has more capacity to store larger volumes of information. There are two categories of long-term memory: (i) declarative memory and (ii) procedural memory [2, 5]. Declarative memory is memory that assists us in knowing ‘what to do’. This memory is all we have experienced in the form of information gained from lived experiences since childhood. This memory stores birthdates, addresses or rules of a game. Procedural memory is the memory storage of skills and procedures and is involved in remembering tasks such as riding a bike, driving a car, skiing, or playing a musical instrument. This is ‘know-how’ memory, which often can only be expressed by performing the skill. When an expert, the person often has difficulty verbalising the steps in a skill recalling procedural memory, as the skill has become so automatic. Once established, skills memorised and stored with long-term procedural memory are often not forgotten even after years of not completing the skill.

There are two primary theories as to why information is forgotten over time: decay and interference [3, 17]. Decay refers to the loss of memory simply due to the passage of time, while interference refers to the situation where new information may displace or corrupt older information. The right retrieval cues can assist with memory information being recalled/recognised. Techniques can be used to assist with the right retrieval, such as environmental cues and completing the task again in the same environment. This may need to be considered when supporting a person to learn a psychomotor skill, particularly where cognitive impairment and memory loss are observed, such as in the elderly and those with respiratory conditions. As can be seen, both theories can easily be a concern for a patient with a respiratory condition. Where an inhaler is only used during an exacerbation of their condition, and exacerbations only occur every 2 years, decay of memory may lead to inaccurate use of the inhaler when the next exacerbation occurs, such as missing a step in the process of taking the drug or having technique incorrect. An example of interference could be the additional of newly prescribed inhalers, which are different in steps taken and motor control required than those previously taken, but are needed to be taken in combination with previously administered inhalers. The new inhaler requires a new psychomotor skill which then 'displaces' the previous learnt skills for the previous inhaler, and the technique for the previous inhaler is no longer remembered accurately.

Facilitating Motor Learning for Psychomotor Skill Development

The principles for facilitating psychomotor skill development are grounded in the theory that learning motor control is centred on the interaction between learner, the goals of the task and the features of the environment (such as if the room is loud/quiet, filled with people/empty of observers, light/dark etc.) for supporting successful attainment of the new skill (Fig. 3.1). The mechanisms for supporting psychomotor skill development consider the learner, the task and the environment in setting up the right circumstances for learning. The first concept to appreciate is the idea of implicit and explicit learning, and internal and external attention to the task.

In the context of learning to use a dry powder inhaler with capsule, the patient component of this interaction may relate to motivation, cognitive impairment, arthritis in the hands or wearing an oxygen mask (see Chap. 13). The goals of the task are specified in an inhaler, being successful inhalation of the dry powder, so this component is clear. In other examples, this may not be as clear, such as distance to

Fig. 3.1 The interaction of processes in learning a new psychomotor skill

be walked by a patient. The environment would be whether the patient takes the drug in the morning in day-light or evening under an electrical light, or whether they are standing or sitting in a chair or at a table.

Explicit and Implicit Motor Learning

Explicit learning is characterised by a learner being provided comprehensive and detailed direction on how to complete the task. Implicit learning involves the learner being provided with little direction beyond indication of the goal to be achieved. Each method of learning has benefits and drawbacks, which will now be explored.

Explicit learning is a more traditional style of coaching. That is, the healthcare professional provides clear direction on what is needed to achieve successful attainment of the goal – the more traditional approach of seeing one demonstrated and then trying to do it yourself with clear instruction on how. The healthcare professional will instruct the patient, either verbally or in writing, on the individual steps and necessary movements to achieve the desired goal of the task. Demonstration of the movement may also be provided. This approach places high demand on working memory and as such requires a certain cognitive capacity of the patient to be able to process the information (i.e. cognitive load associated with the task). The method encourages the patient to have a deep understanding of the *rules that govern the movement*. In explicit learning, the patient frequently sees an increasing ability to verbally explain the details of the movement [15].

Implicit learning is centred on the patient solving the movement challenge and learning the new psychomotor skill through *trial and error* with little input from others. The learner is less likely to be aware that learning is taking place and is not encouraged to form a movement hypothesis or attempt to cognitively engage with the underlying mechanisms of performance [13]. As little instruction or guidance is provided by the healthcare professional, the patient does not develop an ability to verbalise the movement, with the patient internalising the learning process. Implicit learning is considered more patient focussed than explicit learning, which suggests this approach should be ideal in patient-centred care model. However, the approach can leave the patient feeling lost on how to achieve the goal of the task. Additionally, the movement might be learned incorrectly. Benefits to this approach include that the learning process is less likely to chunk the movement into stages, which allows a more stable and flowing movement pattern to form. The approach also places less demand on working memory and is acquired without an early dependence on working memory. Performance is therefore less likely to be impacted by secondary tasks as cognitive load is lowered [34]. In the case of poor memory, implicit learning appears to have a lower cognitive load and may be more appropriate for use with people with hypoxaemia or cognitive impairment [14]. Other benefits to implicit learning include reduced fatigue [12], which may allow additional repetition and practice. Lastly, implicit learning appears to have increased resistance to anxiety as the fine details of the movement are never fully understood [16].

The decision on whether to use explicit or implicit learning approaches depends on the task, the cognitive capacity of the patient and the level of expertise of the patient at the task. However, explicit versus implicit needs to also be considered in the context of external or internal attention.

External and Internal Focus of Attention

External or internal focus of attention refers to how we attend to where we are in terms of body position, the environment and/or the objective to be controlled. External attention is where the learner focusses on the intended movement effect or outcome of the task. That is, they focus on the effects of the movement and how it interacts with the environment. In the case of the dry powder inhaler with capsule, the patient would focus on whether the movement lead to the capsule being pierced for drug dispensation and the drug being successfully inhaled. This is contrasted with internal attention, where the focus is on how the movement is controlled during the task. The patient concentrates on the body movement and techniques' accuracy. Internal attention in learning to use the dry powder inhaler with capsule would see the patient concentrating on where the hand is positioned in holder of the inhaler, whether fingers are flexed on picking up the capsule and how that flexion facilitates inserting the capsule into the plastic inhaler case (regardless of whether the drug is dispensed or not).

External attention enhances motor performance and learning, across a variety of tasks and learners, regardless of age experience or ability [33]. Feedback therefore would focus on the outcome being achieved and direction provided on how the outcome can be achieved. When we focus on the intended movement effect or outcome, the control is more automatic. This results in a more effective movement that is less constrained, and the performer is therefore able to make faster adjustments [32]. In the case of learning to use the inhaler, focussing on the outcome of drug dispensation is therefore more likely to have a greater positive impact than concentrating on the exact position of the hand.

Providing Feedback for Psychomotor Skill Development

Feedback refers to information used by a learner as a basis for understanding how they moved and what can be changed for improvement. Benefits of providing feedback for psychomotor skill development include enhanced goal attainment, and the detrimental effects can include a dependence on feedback, which of course is not always available. Feedback has a motivational role, and there are strong links between feedback and psychology.

Feedback can be described as intrinsic feedback, which is the body's awareness of whether completion of the task was successful through multiple forms of sensory input. This compares with augmented feedback, where information about the performance of the task is provided from a source external to the performer [11]. Augmented feedback is therefore the feedback a patient receives from a healthcare professional. Knowledge of results (KR) is the augmented feedback given after completion of the movement to provide the performer with information about the movement outcome or performance [28]. Knowledge of performance (KP) is the augmented feedback that gives information about movement characteristics that led to the movement outcome or performance [28]. In the example of using a dry powder inhaler with capsule, KR feedback would be focussed on the successful achievement of inhaling the powder with the rattling of the capsule, while KP feedback would be focussed on giving feedback on the precision of inserting the capsule into the plastic casing, including finger positioning and how the capsule is being held. Important considerations in a person obtaining feedback include the type of feedback, the mechanism of feedback, the timing of the feedback and the precision of the feedback. Feedback can be given in many ways, including verbal, visual in real time (such as using a mirror), delayed visual (such as watching a video recording), or biofeedback where information about the physiological processes involved in performing the skill are delivered.

Descriptive verbal feedback informs the learner about the nature of the error in movement they have made. While prescriptive verbal feedback not only identifies the error but also tells the person what to do to correct the error. There is no empirical evidence that demonstrates which is better for motor skill learning, and in general the answer lies with the skill level of the performer. Prescriptive feedback is generally better for novices, while descriptive is more appropriate for experts who have developed an understanding of the movement pattern needed for successful achievement of the goal. In general, descriptive KP feedback is more useful once the learner knows what to do to make the correction and thus improve performance.

Visual feedback can be in real-time or delayed, depending on whether the feedback is attempting to support reflection in practice or reflection on practice. Reflection in practice is where the learner considers their actions and decision-making while they are attempting to complete the task and self-corrects during the performance of the motor task. Reflection on performance is where the learner will consider what occurred, what worked well and what needs improvement after the task has been completed. The use of live visual feedback (such as completing the task in front of a mirror) is best when feedback in practice is being encouraged, while video feedback is best when reflection on practice is to be completed. Interestingly, an over-the-shoulder view may be more effective than a direct mirror-image example, as the mirror view has the complexity of reversal of image. The effectiveness of using visual feedback relies on the expertise level of the learner. In general, visual feedback is less effective for novices unless critical information is pointed out and then supplemented with verbal cues [10]. Visual feedback is also more effective if used over an extended period [23].

Should Feedback Be Given During a Skill or Following?

Timing of feedback is essential in supporting psychomotor skill development and can be considered as concurrent augmented feedback from the ‘coach’ that is provided to the patient, as the intrinsic feedback obtained from the person’s body tends to enhance the performance of the task. Understanding the cognitive load of the patient learning to compete the new task is one of the key drivers for when feedback should be given [35].

Frequency of feedback also needs to be considered, and ideally the frequency of feedback provided should fade [7]. Early in practice when many errors occur, frequency of feedback should be higher, but as the learner begins to develop the skill, the feedback should become less frequent. Summary feedback is the final consideration in frequency. Summary feedback is where feedback is withheld for a number of completions of the task. This allows the learner to practice and internally reflect on performance. However, too many completion attempts without feedback can negatively impact learning, particularly in more complex tasks where larger summaries of feedback are provided. Schmidt et al. [27] concluded that approximately five task completions and then summary feedback was the most effective for learning.

The precision of feedback given is the final consideration. Precision of feedback is the degree of exactness of the information we give to the learner, in either a quantitative or qualitative format. Qualitative feedback general informs the learner if their performance was correct or incorrect and is provided by information that tells them if their performance was too fast/too slow, too hard/too soft, too long/too short. Quantitative feedback indicates the direction and magnitude of the error and is presented with varying degrees. As the precision of feedback increases, so does the amount of processing required by the performer, and logically the time required for this processing also increases. It is important to note that increasing the precision of the feedback is useful for the learner up until a point. Novices should receive less precise feedback, and more general information about their performance is desired in the early stages [7]. For example, in the case of the dry powder inhaler with capsule, the initial feedback early on may be to focus on the rattling of the capsule during inhalation occurring. As the patient practices during the training session and becomes more proficient, the feedback can become more precise on the frequency of vibration and volume. This is done so as not to overwhelm the patient from the very first attempt. The most imperative component is allowing additional time for considering the feedback where the precision of the feedback is higher; ensure the patient has time to think through the feedback given.

Conclusion

Learning a new skill, such as how to take a respiratory medication using a dry powder inhaler with capsule, requires development of knowledge and memory in parallel with motor control. The process that is undertaken to learn a new skill by a patient is complex and not fully understood, but motor control theories can support the healthcare professional to apply the best approaches to facilitating new movements. The intersection between the patient, the task and the environment in which the task is to be completed are the essential components to manipulate in learning. Explicit learning, with external attention on the goal of the movement, appears to support a patient to learn a psychomotor skill most effectively. The stage of learning, whether the person is novice or expert, prior lived experiences and stored movement patterns, and whether the person has any musculoskeletal and/or cognitive impairments may impact on their capacity to learn.

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Chapter 4
Best Practice in Educational Design for Patient Learning

William Kelly, Holly S. Meyer, and Felicity Blackstock

> *The mediocre teacher tells. The good teacher explains.*
> *The superior teacher demonstrates. The great teacher inspires.*
>
> *— William Arthur Ward*

You are running late during your busy morning clinic. Does your patient understand her new asthma inhaler? How can you be sure? And if you send her down the hall to a medical team member for "education," how well do you know what goes on down there?

You are asked to deliver a presentation to patients in pulmonary rehabilitation. Some old slides are available… but should you even use them? What exactly are you trying to accomplish? How do you make the most out of this time investment by the learners and yourself?

You are assigned to a "clinical pathway" team to reduce chronic obstructive pulmonary disease (*COPD) readmissions at your hospital. One box to check on the flowsheet is "patient education." Where do you begin? How will you know if you have been successful?*

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Education is a key component of patient care, with significant potential to positively impact health outcomes through patient empowerment and behavior change. Chronic diseases are responsible for 60% of global deaths and half of its disability [1]. A majority of patients misunderstand their prescription immediately after their doctor's visit [2]. Even inpatients' knowledge about their hospitalization is poor [3]. Nonadherence to therapy resulting in hospitalizations and additional care may incur $100–300 billion in *avoidable* costs annually [4]. Of course, more important to the patient than this financial impact is the harm to quality and quantity of life. Patient empowerment through education has the potential to improve all of these outcomes. Indeed, a 2018 review of chronic illnesses [5] found 46 of 56 published patient education interventions meeting inclusion criteria showed reduced hospitalizations and clinic visits, improved quality adjusted life years, or productivity. In an era of increasing demands while time and other resources decrease, best evidence-based practices in educational design for patient care are necessary. Proving specific patient education models that are of value is important; however, this has been challenging due to the heterogeneity of interventions and populations studied. However, this should be viewed as a significant opportunity rather than a limitation. A recent study [6] of callers with COPD to a smoking cessation line found that over two-thirds wanted disease-specific information and less than one-third had received instructions on key elements of non-pharmacologic management. Such patients' desire for educational opportunities to improve their health can and should be leveraged. The expanding diversity of educational design options creates an exciting mandate to transform patient education. As a disclaimer, our following discussion of design comes from medical education, which can be generalizable to patients as long as potential literacy, culture, and physiological obstacles are kept in mind.

Analogous to clinical care, patient education should consist of making a diagnosis (needs assessment), an intervention (in this case educational activities and teaching moments), and then follow-up for effect (re-assessment). An educational "diagnosis" involves (1) recognizing what your patient needs to know (cognitive), feel (affect), or do (psychomotor skills), (2) deciding if they are motivated and able to do so, and (3) reflecting on your own teaching capacity (your own skills and institutional support) to determine how the intervention can be designed. The therapeutic "intervention" of education is the content and method of delivery (format). Like all therapies in medical practice, education could have risks (misinformation), side effects (increased patient anxiety), and unintended consequences (increased utilization). Formal assessment to see if the educational therapy worked or not, and how to improve, should be part of patient "follow-up." Finally, education should be culturally responsive and free of bias [7].

"Diagnosing" Your Learner – Patient

The ultimate goal of patient education is to provide an experience that is transformative and improves HRQoL. While much well-intentioned time and resources are spent on delivery of information to patients, more thought should go into understanding beforehand who the learner is and what the learning objectives should be. What does your patient already know, and what else do they need to know and why? What needs to be learned depends on a patient's capacity to change his/her health behavior, such as for safe discharge or a new medication regimen. Most pulmonary professional societies provide information for patients based on expert consensus or intuition. These can be an excellent source of initial guidance for clinicians designing a program of patient education. These, usually free, resources prevent you from "reinventing the wheel" (Box 4.1). But not all topics may be considered relevant by patients, and some relevant topics, such as financial and social support issues, are often not included.

Box 4.1 Potential Resources

Links as you develop your education materials

Health literacy guides, resources, and tools
https://www.plainlanguage.gov/resources/content-types/healthcare/

Patient Education Materials Assessment Tool (PMAT)
https://www.ahrq.gov/professionals/prevention-chronic-care/improve/self-mgmt/pemat/index.html

Links to share with patients:

American Association of Cardiovascular and Pulmonary Rehabilitation
https://www.aacvpr.org/Resources/Resources-for-Patients/Pulmonary-Rehab-Patient-Resources

CHEST Foundation – American College of Chest Physicians
https://foundation.chestnet.org/patient-education-resources/

American Thoracic Society
https://www.thoracic.org/patients/patient-resources/

American College of Chest Physicians – Patient Education Center
https://www.acponline.org/practice-resources/patient-education/online-resources/breathing-and-lung-health-respiratory

Lung Foundation Australia Pulmonary rehabilitation toolkit (COPD)
https://pulmonaryrehab.com.au/importance-of-education/resources/

Learning should be contextualized, being where an individual patient's circumstances (their context) are identified and learning is tailored to the circumstances and needs of the individual. To do this, you must first assess a patient's starting point or knowledge baseline. This can begin with open-ended inquiry during your patient interview. Taking the time to ask questions about lived experiences associated with their pulmonary diagnosis, other past medical conditions, confidence and capability with using technology, digital technology access at home, and about degree of success navigating the healthcare system develops your understanding of their health literacy. In addition, several validated questionnaires are available to support the clinician to quantitatively evaluate knowledge, health literacy, or digital literacy. Patient demonstration of skills can be done using a checklist (see assessment section below). Using a teach-back method [8] can be especially enlightening. This is also known as "show-me" method, in which the patient tells or shows what was just taught to them, allowing the healthcare professional to confirm comprehension and understanding.

Simply knowing what your patient needs to know is not enough for transformation of behavior and improved health outcomes. As Redman points out in her book, The Practice of Patient Education [9], individual motivation and cognition must also be considered. The patient must be motivated to expend the energy required (for new knowledge, skills, or attitudes) to ultimately change behavior. Motivation can be an intrinsic need to be competent, autonomous, and related to others, but also to any external reinforcement. Personality also comes into play, as there are patients who are "monitors" who benefit from more details versus "blunters" who may do better with less information [10]. Learning new skills increases motivation and a sense of self-efficacy. Self-efficacy has been associated with better HRQoL and better disease-specific health status during pulmonary rehabilitation [11]. But repeated failure can break one's self-efficacy. Instruction should match the patient's stage of readiness at any one time. Chapter 6 explores the power of motivational interviewing, while Chap. 11 explores self-management strategies bringing further insights to these concepts that can influence learning and behavior change. Mood disorders are increased in some pulmonary conditions, such as depression (8–80%) and/or anxiety (6–74%) in COPD [12], so Chap. 5 provides insights into assessment of mental well-being, while Chap. 7 provides guidance on interventions to support people with clinical anxiety and depression. Additional strategies must be considered during learning activities when motivation and mental health may be impacting the capacity to learn.

Adding to this challenge, 61% of patients with COPD have some cognitive impairment [13], which could impact on their capacity to remember, perform skills, and make decisions – all of which are essential to transformative learning. When a patient does not understand their diagnosis or treatment plan, adherence is compromised [14]. This does not mean that education should not be attempted. Instead, special attention to timing, method, and frequency of reinforcement may have to be adjusted. Assessment of cognitive capacity is essential prior to commencing an educational intervention. Readily available screening tools can support the process, including the Montreal Cognitive Test (MoCA) that can be administered in under 10 minutes, or the Mini-Cog (clock drawing test plus 3-item word recall) is even faster [15]. Clinicians sometimes avoid assessment of cognition, fearing it to be too confrontational, but focus groups suggest patients with pulmonary disease understand and appreciate the need to do so [13]. By understanding where the patient is commencing their learning journey, educational activities can be designed to meet that person's level. Failing to do this can result in educational disengagement, which can damage learning, self-efficacy, and behavior change.

Finally, reflection is at the core of learning, and it takes reflective practice to diagnose one's own efficacy in teaching and learning. Do you have the requisite knowledge, skills, and time to do this teaching and facilitate patient learning and behavior change? If not, how will you get it? Or whom do you refer the patient to?

Clinician educators' self-efficacy has been linked to their perceptions of students' competencies [16]. Developing your teaching capabilities across your career lifetime may positively impact patient outcomes. Further, you are role modeling learning to your patients. Role modeling is a powerful mediator in transformative learning, as respectful relationships underpin learning.

The "Therapy" (Designing the Educational Intervention)

Patient education, like any other therapy, requires the healthcare professional to start with the end in mind. What capabilities does the patient need to have (i.e., knowledge, skills and attitudes) by the end of your time together? Prioritization is necessary as not all aspects of learning can be addressed at once. Some things may be desirable but not absolutely necessary to know (aspirational), while others would be mortifying to you if your patient were unaware. Which capabilities should be developed first as core to improvement or foundational for further learning?

In the education field, starting with the end in mind is referred to as backwards design [8]. Learning goals and objectives are decided first before any teaching materials. This keeps focus on outcomes instead of teaching styles or processes. Such a thoughtful approach is necessary, as educational interventions may not be entirely benign. If not done well they can lead to confusion and loss of a learner's sense of self-efficacy and confidence. In a 2017 Cochrane review [17], self-management interventions in COPD were even associated with a slight excess in respiratory-related (but not all-cause) mortality. Of course, other factors might have also influenced the outcome, but results demonstrate the potential for adverse effects. Education therefore should be "prescribed" with evidence-informed approaches and monitoring of effect.

Backwards design for creating educational activities involves three fundamental components: (i) objectives – identifying what the patient needs to know and/or do, (ii) assessment – determining how the healthcare professional will know if this knowledge has been attained, and (iii) teaching methods – utilizing the best teaching modality for that content and situation.

Effective objectives are the necessary first step to focus the education process, identifying what capabilities the patient needs to have, know, and (depending on the circumstance) do. Ultimately, one needs to convey "who, will do, how much or how well, of what, by when" [11] in order to consider your patient education to be successful. This is what makes objectives well "formulated" or follow the best formula. For the patient, the objectives focus attention on critical elements. For the healthcare professional, objectives guide what to teach, suggest the effective instructional methods to use, and enable evaluation of the teaching provided. It is important to note that writing objectives is an iterative process. The healthcare professional should re-visit their formulated objectives frequently, reflecting on outcomes to ensure the three components (objectives, assessment, and teaching methods) are in continual alignment.

There are many different ways that educators talk about writing objectives. Specific, Measurable, Achievable, Relevant, and Time Bound (SMART) [18] is one of the most common and simple methods for writing them, and aligns with patient-centered goal frameworks frequently used in healthcare:

Specific – who is being taught and what is being taught and to what extent. Is it the patient, a caregiver, or both? The depth and breadth of content shared is important given the duration of a patient's visit, the capacity of the patient to absorb information at that moment, and the patient's prior knowledge.

Measurable – what action can the learner take to satisfy your objective?

Achievable – can the patient accomplish this? How much content can the patient absorb in the time you have together? Is it feasible to do within your clinical setting?

Relevant – is this important and practical for the patient? Getting such buy-in is an important component of adult learning.

Time Bound – what is learned should be something your patient has to use in a timely fashion – not be applicable years from now. When should the objective be complete? Usually, it is by the end of your educational session, though should be reinforced over time.

One example would be teaching a frail patient and his spouse (specific) the eight steps in ideal rescue inhaler use (measurable with a checklist) in clinic today by the respiratory therapist with 15 minutes after pulmonary function tests are completed (achievable), so that the patient may have some relief from exacerbations of his dyspnea (relevant), and that he can demonstrate proper usage at the end of clinic visit and then when seen at start of next appointment in 6 weeks (time bound).

SMART learning objectives require an active, measurable verb and the articulation of observable and specific knowledge, skills, and/or attitudes. Identifying an appropriate and descriptive verb is critical for setting clear expectations around precisely what a patient is intended to know and do. For example, the verb "understand" COPD exacerbations is passive and vague. But "list" three signs (change in cough, dyspnea, wheezing) is active and clear. Bloom's taxonomy [19, 20] (See Fig. 4.1) provides a hierarchy of active verb choices that can be aligned with a measurable assessment. Choosing the best verb requires determining what type of thinking and/or actions the patient needs. Generally, learners need to be capable of the lower levels of the taxonomy before moving up the pyramid. As such, healthcare education should consider the lower level thought processes and capabilities of patients to be foundational, and assess and develop these before proceeding further.

Kern's textbook [10] on curriculum development recommends making a table to structure the design process. Whether it is a cognitive (knowledge), affective (belief, value or behavior), or psychomotor (skill) outcome, the educational designer needs to list the learning objective, the method and practice of teaching it (referred to as pedagogy), the reinforcement (what you will do to prevent decay of any learning that was achieved), and then the resources required by the teacher and learner. See Fig. 4.2 for one such table with one example in each of the three domains for COPD. The resources element cannot be overemphasized, as it impacts all others.

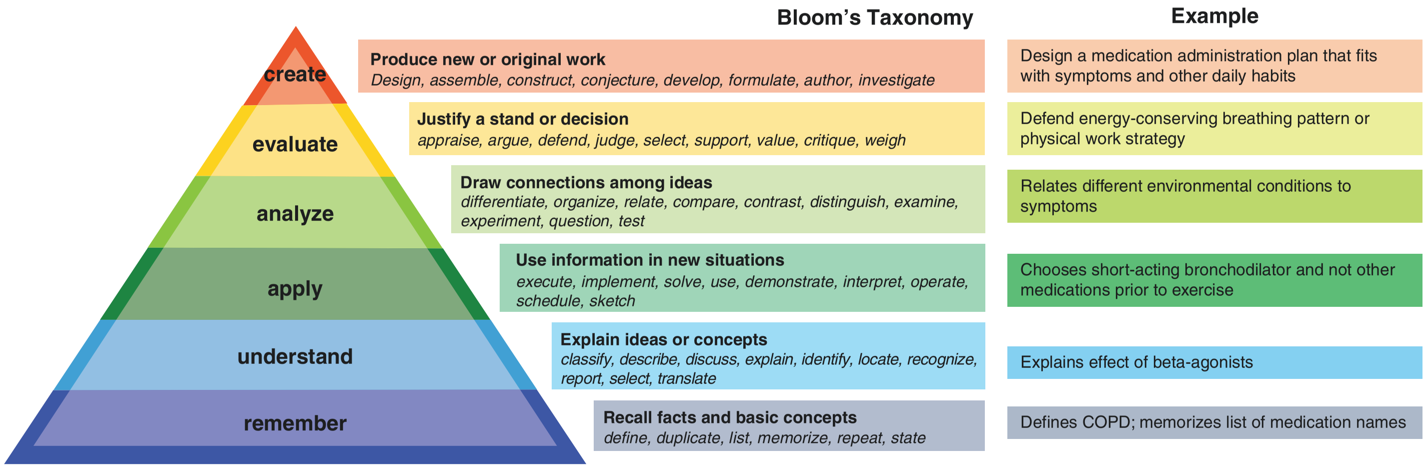

Fig. 4.1 Clinical predictors of biphasic anaphylaxis

	Cognitive (Knowledge)	Affective (Attitudinal)	Psychomotor (Skill or Performance)
Specific measurable objectives	1. Recall the primary medications used in the management of COPD	1. Understand the necessity for adherence with medication routines	1. Accurately self-administer X medication using Y inhaler device
	2. Understand the process by which the medications affect the lungs to improve symptoms	2. Recall the adverse events associated with lack of adherence with medications	
		3. Adhere with personal medication routine for at least 1 week	
Educational method to achieve learning objective	1. Lecture to the group giving overview	1. Development of medication routines, that are individually tailored and structured by the patient with support from the PR professional	1. Demonstration of technique for inhaler use–live during the PR class, and available as an online video for viewing at home
	2. Small group discussion among peers, completing interactive activity on how the lungs work and different drugs influence their function.	2. Peer discussion on the issues when medication routines are not followed.	2. Repetitive practice with peer observation and review
			3. Patient films self, taking inhaler and uploads to YouTube for peers or PR professional to review and provide feedback.
			4. Final review by PR professional to confirm technique correct–if incorrect, repetitive practice with peer feedback then repeat assessment by PR professional until correct technique
Educational method to prevent decay	1. Quiz on the different respiratory medications and modes of delivery	1. Review of medication routine	1. Review of inhaler technique weekly for 4 weeks to ensure remains correct–practice in front of peers, then assessment by PR professional.
	2. Quiz on the process by which medications influence the lungs	2. Diary of medication use for 1 week, with peer discussion on when medication routines are not followed–what are the challenges and how can you overcome?	
Resources required	1. Microsoft PowerPoint	1. Diary to document medication routine.	1. Placebo inhalers
	2. Data projector and lap top	2. Diary to document medication adherence over the week following.	2. Online platform with video of PR professional, for example YouTube clip
	3. Activity sheet for completion during the class–includes discussion activities that foster development of understanding not just memorizing.		3. Instruction sheets for reading of steps to take medication.

Definition of abbreviations: COPD = chronic obstructive pulmonary disease; PR = pulmonary rehabilitationa

Fig. 4.2 Exemplar of curriculum design for pulmonary rehabilitation: inhaled respiratory medication use. (https://www.thoracic.org/statements/resources/copd/copd-disease-education-in-pr.pdf)

Pedagogy is the method or practice by which a teacher will engage with a learner to support the process of learning. There are many different approaches described in educational literature including didactic, inquiry-based, partnership, and learner-centered. Pedagogies vary greatly as they reflect different social, cultural, and political contexts. Indeed, consideration of the culture of the learner is critical considering the health and healthcare disparities observed across cultural groups globally. Extensive exploration of pedagogical approaches is beyond the scope of this chapter, although readers are encouraged to consider their current strategies and how to enrich their patient's learning experiences, with additional patient education texts available for further reading [9, 21–23].

Education is often experienced in group settings, which has the advantage of efficiency, but more importantly allows for sharing experiences and peer modeling. Group-based activities usually consist of lectures or presentations, or group discussions exploring cases/scenarios, or practicing psychomotor skills development. Lectures or "large group didactics" are common for cognitive domains (knowledge) because they are so feasible due to the small teacher: patient ratio and little necessary special equipment. PowerPoint slides are frequently used but can be counterproductive if containing too much text, red-green colors, or distracting fonts or animations. Published guides [24] are available to support you in creating slides for learners that support avoidance of animations, of certain fonts and colors, and of excessive text. Group teaching can also decrease social isolation, and "social comparison theory" (peer pressure) can improve performance [25]. While large group teaching is efficient at delivering content, it relies heavily on the speaker's skills to engage in one-way communication leading to disengagement and inattention. Opening with a story and strong voice and ending with a call to action are a few of the recommendations of speaking coaches. Case-based learning can be more engaging, where learners are provided with a scenario and given structured questions to discuss and answer about the case. Case-based learning can be structured to first require individual learning at home (and often online), then individuals come together for discussion and to make meaning of the material they have been provided. This "flipped" classroom model [26] brings efficiency to the face-to-face education session but relies on motivated learners to complete the prework.

Learner attention wanes after 15–20 minutes, so it is important to insert breaks or engaging activities (for examples, see below) to reset this clock, for both online and face-to-face learning activities. A one-hour video online is rarely watched in entirety. Rather 7–10 minute online experiences can be completed as small learning "moments." This attention span challenge is even greater when cognitive impairment is present. Learners with poor memory can be helped with even shorter, more frequent sessions, use of memory aids such as pillboxes (medication container labeled with days of the week to indicate to the patient which medications are to be taken when), and diaries to record their activities and support their reflections for learning.

A related phenomenon to consider in the delivery of educational experiences is the primacy-recency effect. Learners will most remember the beginning of an educational activity, followed by the end, and may miss much of the middle. So start out with the most important principles in order to not squander this precious peak-attention time. One no-cost way to engage an audience is the "pause procedure" [18] where one stops and gives learners 2 minutes to review their own notes or just think about what has been presented. This can also be done in the form of a "pair-share" where they briefly discuss with their neighbor in the group. Audience response systems [27], such as several hand-held "clicker" devices or free applications on smart phones, can maintain attention with the forced choices helping to encode memories. Even a show of fingers can be used to answer multiple-choice questions ("A" is one finger, "B" is two, and so on) and directly engage the audience in thought about the topic. This also gives the teacher real-time visualization of how well the group understands the concepts being presented and whether learning is taking place. The presenter can then either re-visit the concept during this presentation or later make modifications to the presentation considering the audience engagement and ability to grasp concepts. A final, and critical, component of a teaching encounter is the closing [28]. This involves recapping the key points and then providing patients with the opportunity to clarify their understanding.

Discussion so far has referred to live educational activities. Frequent attempts are made at informing patients through the asynchronous use of printed, video, and/or online resources. In a 2008 survey [29], 75% of healthcare professionals reported routinely handing out patient education materials. However, many media-related educational resources are sub-optimal, with 30–100% written above the recommended sixth-grade reading level [30]. Half of the population may struggle with reading, and actual reading level may be five grades below the patient-reported grade level completed. The Institute for Healthcare Improvement provides a readability checklist [31] covering seven design elements for printed materials you may be creating or considering using. Tips include use of second-person voice, bulleted main points, and images. The Agency for Healthcare Research and Quality developed the Patient Education Materials Assessment Tool (PEMAT) [32] to evaluate the understandability and actionability for either written or audiovisual material.

Use of health information on the internet is a specific subset of literacy, and this digital or “e-literacy” in the United States is also low, ranging from 26% to 50% of the population (90 million people) [32]. Online health sources are used by more than 70% of people surveyed and are often the first source used. But publicly available websites frequently exceed the recommended reading level. In one study of lung cancer [33], the mean reading level of websites was eleventh grade. Reviewing the available online resources for people with COPD, Stellefson et al. [34] (2014) and Paige et al. [35] (2015) found, through a social media content analysis of YouTube and Pinterest, respectively, that content and quality varied significantly with many low-quality resources readily available to patients. Also, many websites are not yet mobile-enabled, which misses out on the growing portion of the population that conduct all of their business exclusively on smartphones or tablets – and an opportunity for us to seamlessly insert incidental education as they do so. These findings demonstrate that online learning design is not a simple “make a website” approach for patient education. Experts in digital and technology-enabled learning are available to support healthcare professionals in shaping content for efficient online learning that is active and appropriately presented through digital media. Digital educational experts should be consulted when creating online learning activities as healthcare professionals should not be expected to necessarily have this expertise. Well-designed virtual education and “telehealth” may help compensate when face-to-face education options for patients with chronic illness are less viable or accessible [36]. A 2018 systematic review suggested this was as, or more, effective than usual care in outcomes including knowledge, self-care, HRQoL, and healthcare utilization [37].

Affective domains, being attitude changes, require even more time and reflection such as diaries and journals in a continuous reflective cycle. Reviewing one’s own adverse events or listening to such stories of peers can be an effective emotional trigger for patients that provides motivation for behavior change. A disease flare up including hospital admission can be a significant life event, creating a “teachable moment" because of emotional activation and perceived relevance for learning. For example, patients admitted with a COPD exacerbation randomly assigned to patient education had improvements in *global* HRQoL – which was relatively unique to this study population [38]. The use of reflective frameworks, for example, Gibbs Reflective Cycle [39] to support learning, can guide both the patient and the teacher through a reflective process and support transformative learning.

An emerging new area of educational design is "games for learning." As the digital world shapes society and how we function, it also shapes how we learn and provides new opportunities for connection. Video games appear to be an effective media as they are a powerful tool to manipulate behavior. Engagement, rapid feedback loops, and their visual nature (as compared to passive reading of information) encourage active learning. "Leaderboards" dynamically rank an individual patent "player" as compared to their peers (peer pressure or "peer comparison" effect). If use of quiz questions with a leaderboard can improve glucose control in patients with diabetes [40, 41], think of the potential for those with obstructive pulmonary disease. Other game "mechanics" include giving a digital badge or reward for good performance. A main limiting factor in gaming for patient education is resources to create the interactive digital platform. However, as technology expands and costs associated with computer hardware and software decrease, the potential for gaming in healthcare increases. The challenge will then be in understanding the most effective educational design features needed in gaming for learning to change health behavior. Lessons can be learned from the higher education sector on the theoretical foundations for gaming for learning [42] to pilot new educational interventions with patients and establish the evidence for gaming as a new model for patient education.

Developing Better Teachers Through Feedback

Published focus groups describe the best patient educators are those who demonstrate sensitivity and provide individualized education, noting that a supportive environment and intrinsic motivation are key factors [43]. To maximize the capabilities of the healthcare professional leading educational activities, and thereby their educational impact, one's own teaching skills require direct observation and feedback. Videotaping education sessions for later personal reflection can be effective. Peer review, inviting a colleague to support your reflection and debrief afterwards, can also be a rich learning experience for the presenter. Learners are an invaluable source of feedback on teaching approach, and taking the time to gather the patients' perspective is essential for professional development in the practice of facilitating learning [44]. Feedback from multiple perspectives is more comprehensive ("360 degrees"). This evaluation can be through formal surveys or focus groups at the conclusion of learning activities. Just simply asking a patient for feedback at the end of a teaching session or the entire PR course may also provide insights for improvement of both the activities used and your own teaching.

The Follow-Up (Assessment of Educational Effectiveness)

It is important to assess whether your educational intervention actually worked, confirming attainment of the learning outcomes originally planned. The ultimate outcomes would be the individual's or community's health and healthcare utilization. But shorter term measures of the educational intervention are more feasible, such as score on a checklist of observed inhaler usage technique at the end of a teaching session or NIV compliance data at the end of a month. There are many ways that a patient can be assessed for learning [45], including validated learning needs questionnaires, such as the Lung Information Needs Questionnaire (LINQ) [46] measuring change in knowledge scores pre- and post-education. However, these questionnaires are limited to the patients' perception of knowledge and do not measure learning of skills or changes in affective domains. Teach-back, or "show me" method, as discussed above [8], is an easy method in which the patient has to repeat, in their own words, what they have done. This closed loop communication is a quick, real-time tool during the patient encounter and can include knowledge, skills, and affective domains in the review of learning. Other tools, which are usually designed specifically for the educational activity, depend on measurements aligned with that table you completed during the planning phase. Quizzes are best for testing medical knowledge. Knowing there will be a quiz later can improve learning by adding emotional accountability, even when a test is considered to be low stakes. Team-based or anonymous quiz answering can remove any patient anxiety and still serve to assess the teaching program, but are less useful in assuring that any one individual benefited. Test question writing, especially multiple-choice format, requires considerable thought, as there are several pitfalls that need to be avoided [47]. True–false questions encourage guessing, while emphasis on trivia is not practical. As in other aspects of education, a clear link between the test-question and the learning outcome being measured is necessary. Finally, a procedural checklist, especially if validated [48], used when a patient is demonstrating a skill such as inhaler usage is the best way to quantify and trend skills improvement over time.

Setting small frequent goals can be reinforcing for both the patient and the teacher. Learner satisfaction is considered a low-level outcome but is important in patients' recall and can affect their motivation for ongoing involvement in educational activities and maintenance of behavior change. In one study of asthma patients, satisfaction seemed to improve with longer and more intense educational sessions with no "saturation" or ceiling effect [49].

Conclusion

Patient education is a longitudinal, iterative commitment that can improve patient health including HRQoL and reduce utilization. It may contribute to "high value care" or at least sometimes reduce low value care. It has been said, "management of chronic airways disease is 10% medication and 90% education" [50]. Just like your approach to any clinical dilemma presentation, your patients' educational needs require a diagnosis (needs assessment), a therapeutic intervention (education guided by SMART objectives), and then follow-up to see if outcomes were achieved (assessment).

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Chapter 5
The Impact of Self-Efficacy on Behavior Change: The Roles of Socio-Cultural and Mental Health Factors

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Examining Agents of Behavior Change Among Patients with Pulmonary Diseases

Given the prevalence, morbidity, and mortality associated with chronic pulmonary diseases, clarifying psychological factors that impact behavior change and support mental health in patients with pulmonary diseases is critical to long-term management of the disease. The successful treatment of chronic pulmonary diseases is often inherently linked to a patient's day-to-day behavior such as initiating a smoking cessation plan, regular exercise, improving diet, and adherence to treatment regimens [1–4]. However, a number of sociocultural, psychological, and behavioral factors can interfere with a patient's ability to implement behavior changes that would best support their health and health-related quality of life (HRQoL) in the long run. These patient-specific variables likely play a major part in the fact that chronic, often preventable, diseases are now the leading cause of disability worldwide [5].

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The current chapter focuses on the role that sociocultural and psychological factors play in the management of pulmonary diseases through the construct of self-efficacy [6]. We provide a brief overview of self-efficacy and review sociocultural and psychological factors that impact self-efficacy. This relationship will be personified through a case vignette to highlight examples of effective behavioral interventions for patients with pulmonary diseases (Table 5.1).

Our goals for this chapter are for readers to:

1. Develop an understanding of self-efficacy and the role that sociocultural factors have on health behaviors among patients with chronic pulmonary diseases.
2. Understand how comorbid mental health conditions affect disease processes in chronic pulmonary diseases and illustrate how improving self-efficacy can support behavior change.
3. Identify factors that increase risk for poor physical and mental health outcomes and learn practical and applicable strategies to improve patient care.

Mr. Smith is a 62-year-old, Caucasian, divorced, male with chronic obstructive pulmonary disease (COPD), congestive heart failure, and radiculopathy. He has a history significant for depression and opioid use disorder. He started misusing oxycodone five years ago after it was prescribed to him following a work-related back injury. He has been abstinent from opioid use for six months. He believes that he should be able to "pull himself up by his bootstraps" but is struggling to make changes. He is smoking approximately 15 cigarettes per day. Mr. Smith is presenting to your clinic for a follow-up visit.

Perceived self-efficacy is defined as patients' beliefs about their capability to engage in behaviors that exercise influence over situations and impact their lives [7].

Self-efficacy, or having the capacity to exercise control over one's HRQoL, plays a vital role in the management of chronic disease [3, 8]. Self-efficacy beliefs determine patients' emotions, thoughts, behaviors, and how they motivate themselves, which can sway them toward or away from healthy behaviors [7]. If Mr. Smith believes, *"I have already broken my body so nothing I do will improve my health,"* then it will be much more difficult for him to self-motivate and engage in positive health behaviors. Individuals with high self-efficacy attribute their failures to

Table 5.1 Past medical history for subject of case vignette: Mr. Smith

Demographics	62-year-old, Caucasian, male, lives independently, on disability, unable to work
Medical history	Stage II, moderate, chronic obstructive pulmonary disease; congestive heart failure; radiculopathy
Psychiatric history	Major depressive disorder, recurrent, with anxious distress; opioid use disorder, in early remission
Social history	Divorced four years ago from his wife of 37 years after continuous and problematic opioid use. He has three adult children and seven grandchildren, with whom he has little contact because of his children's concerns about his history of substance misuse. He spends little time outside of his house with the exception of attending community-based support groups for his opioid addiction.

modifiable reasons such as inadequate effort or knowledge, rather than believing their failure is due to an immutable personal flaw. Indeed, individuals with high self-efficacy are likely to persist in the face of challenges and will consistently adapt their choices.

Lasting changes in self-efficacy and behavior are achieved by increasing how confident a person feels across different situations [9]. These incremental experiences of mastery will help build one's confidence over time. For instance, if a person who recently quit smoking is able to turn down a cigarette offered outside of a bar (a "high-risk" situation they have identified to their healthcare professional), they may feel more confident that they can refuse cigarettes in other difficult situations.

As a patient feels more confident and capable to engage in adaptive health behaviors, self-efficacy increases across a variety of contexts and increases overall positive behavior change. Additionally, high perceived self-efficacy is associated with higher HRQoL, reduced mental health symptoms, and more positive treatment outcomes in a number of pulmonary diseases including children with asthma, smokers, and patients with COPD [10–12].

Self-efficacy to maintain and engage in treatment of a chronic disease, such as a pulmonary disease, is affected by a number of psychosocial variables including mental health and sociocultural factors (e.g., family of origin, religion, access to health care, and a patient's relationship with his/her healthcare professional). We will review these factors and how they can impact the successful management of disease in pulmonary patients.

The Role of Culture on Self-Efficacy and Behavior

Mr. Smith has seen many of his friends die from health complications after years of heavy substance use. In the back of his mind, he holds some fatalistic beliefs that "the damage is done." He answers your questions respectfully but quietly and with minimal details, often providing one-word answers. His eyes seem to be fixed on the floor or off into the distance. As you try to engage him in an attempt to help, you recall from your original history and physical that Mr. Smith's uncle died of complications related to a coronary artery bypass when Mr. Smith was a young child. Mr. Smith had mentioned that he and his family have been very wary of being in the hospital since that time, and his aunt went so far as to tell the family she would "NEVER" go back to the hospital for "ANY REASON."

While researchers largely agree on the empirical importance of culture in health care, they have long struggled to agree on a unified definition. Culture is defined here as socially shared beliefs, norms, practices, expectations, and values of society [13–15]. It is imperative to consider how the social and cultural spheres (e.g., work environment, family environment, and shared values) in which patients exist affect their self-efficacy. Social conditions and institutional practices are outside of a single individual's control. Therefore, having the experience of feeling capable of enacting change in life often depends on how well an individual can function within a sociocultural framework. The extent to which *healthcare professional*s treating pulmonary diseases can consider the role of *both* cultural and psychological factors can have on disease processes, the more targeted treatment will become.

Socially shared cultural beliefs have been found to influence the course of a pulmonary disease. For example, the belief that a patient with COPD self-inflicted his/her health problems by smoking has strengthened as social awareness of the relationship between disease and modifiable risk factors (e.g., substance use and diet) has increased. Among a Norwegian sample, individuals ultimately internalized the societal stigma surrounding COPD that the disease is *their fault* and had the psychological experience of feeling "exiled in the world of the healthy" due to their choice to smoke [16]. These internalized thoughts ultimately can result in shame, guilt, resignation, and despair, which, in turn, may reduce a patient's sense of self-efficacy to manage his/her illness. Patients with lung cancer also report intense stigma surrounding the diagnosis and express being unjustly blamed for their illness. Some lung cancer patients go so far as to try and conceal their illness [17]. Indeed, patients who perceive stigma experience higher levels of psychological distress and a poorer HRQoL [18]. Despite the intentions of those who care for them, these individuals often feel rejected by their healthcare professionals and family members during the course of their illness. This rejection may reduce motivation to engage in recommended treatment and attend regular follow-up visits.

In addition to socially shared beliefs around the disadvantages of smoking, socially shared beliefs about the "advantages of smoking" reveal an example of the downstream effects that cultural factors can have on self-efficacy to engage in health behaviors. In a qualitative study of foreign-born Chinese-Canadians, socially shared beliefs about the advantages of smoking (e.g., it gives me energy, gives me a break, and it is fun) can often maintain smoking behavior after a diagnosis of COPD [19]. Such studies demonstrate that self-efficacy is not only associated with *individual* mastery (e.g., smoking cessation), but also the belief that making a health change has a *social purpose* (e.g., my family will not be exposed to second-hand smoke) and can result in widespread communal change when implemented within one's social sphere of influence [20].

One of the most well-studied cultural factors that impacts health behavior is fatalism, or the belief that events are predetermined and inevitable. Among patients with lung cancer, higher fatalistic beliefs are associated with advanced stage diagnosis. Examples of cancer fatalism include "if bad things happen, it is because they were meant to be" and "patients die when it is their time to die and nothing can change that." Interestingly, the patients in this high fatalistic sample were also younger, more likely to be current smokers, and had a *lower* number of comorbidities [21]. Fatalistic beliefs, in combination with low self-efficacy, can result in patients feeling despondent about their health. For example, someone may believe that fate is stacked against him/her because he/she has asthma related to growing up in a polluted area. When exercising, they feel more asthmatic and decide to not exercise anymore because the symptoms are "out of their control." This results in inactivity, weight gain, and further exacerbates their asthma, perpetuating the belief that bad things are always going to happen to them.

Addressing Sociocultural Factors Within the Patient–Healthcare Professional Relationship

Healthcare professionals can more easily identify and target variables that interfere with the treatment of pulmonary diseases by being conscientious of the cultural and psychological factors that are associated with health behaviors. It behooves healthcare professionals to consider the impact culture has on patients, the relationship between the healthcare professional and the patient, and on healthcare professionals themselves. Being aware of these factors will help healthcare professionals better understand variability in treatment adherence behaviors among pulmonary patients and respond in ways that are culturally sensitive and support self-efficacy.

First, it is imperative that healthcare professionals do not blame cultural factors in and of themselves for a patient's difficulty in managing their disease. If a healthcare professional holds competing socially shared beliefs (e.g., Western medicine is superior to alternative treatments) without attempting to reach a middle ground, a rupture in the patient–healthcare professional relationship may occur [22]. These ruptures are often covert; rather than resulting in a discussion, patients may simply not return for care with that healthcare professional or clinic. Maintaining empathy with socioculturally diverse patients gives patients space to openly discuss their thoughts and concerns about treatment plans and improves care [23]. Ultimately, honoring and accepting various beliefs that patients hold regarding their healthcare can lead to productive conversations about meeting treatment goals and improve the patient's sense of self-efficacy.

Second, it is important for healthcare professionals to recognize that patients from ethnic minority groups report disproportionally high levels of negative patient–healthcare professional interactions, including unfair treatment, longer wait times, poorer communication, and experiences of disrespect [23]. Such experiences correspond with a lower likelihood of receiving needed health screening, a lower likelihood of following their healthcare professional's advice, delayed care, and/or reduced continuity of care [22, 24–27]. Such experiences may result in negative beliefs about healthcare professionals in general and behaviors that appear counterintuitive to wellness. Acknowledging that cultural factors play a role in management of pulmonary diseases opens the door for self-efficacy enhancement because patients feel validated by their healthcare professionals. For example, when a healthcare professional acknowledges a patient's fatalistic belief that nothing they do will make it easier for them to breathe, the healthcare professional then has an opportunity to link coping with dyspnea to something of deeper value such as increasing the patient's ability to play with their grandchildren by completing three cycles of a deep breathing exercise.

Lastly, the opportunity to enhance self-efficacy and improve the health of pulmonary patients may be lost when cultural factors are missed. For example, in communities where smoking is more commonplace and health education is less accessible, the healthcare professional and patient can come to a shared agreement about ways to curb smoking within their social group (e.g., ask house guests not to smoke). While socially shared beliefs are difficult to change, highlighting alternative socially shared beliefs that support healthy behaviors such as familism (i.e., putting the family before the individual through loyalty, reciprocity, and social support) can be a more effective way to increase positive health behaviors than challenging a patient's belief system [28, 29]. Working within a patient's cultural framework can support healthy behaviors and improve well-being.

Mental Health and Chronic Disease

Mr. Smith appears distracted as you review his chart, asking you to repeat your questions when you attempt to assess his functional status. His eye contact is poor, he shifts positions in his seat frequently, and he yawns, stating that he has not been sleeping well lately. Mr. Smith appears mildly disheveled and his affect is forlorn. He states that he rarely uses his oxygen tank, and you recall that he has missed many of his previous appointments with you. He states that he wants to feel better but has low energy and "things just keep getting in the way" of attending visits. He says that he wants to spend more time with his grandchildren, but he doubts that he will live long enough to watch them grow up. Moreover, his children do not want him around his grandchildren so long as he is still smoking.

The association between mental health problems and chronic disease has been well documented. While mental health conditions are, in and of themselves, associated with significant global disease burden with a prevalence ranging from 2% to 15% in the general population [30, 31], individuals with chronic disease are at increased risk for experiencing a comorbid mental health condition. A wide-reaching global study examining the relationship between mood disorders and chronic medical diseases found that diagnosis of a comorbid mood disorder (such as depression) was associated with increased risk of a comorbid medical diagnosis including arthritis, ulcers, heart disease, back and neck problems, chronic headaches, and chronic pain [32]. Researchers and clinicians across multiple disciplines have made efforts to better understand the strong relationship between mental and physical health.

Given the chronicity and strong reliance on self-management of symptoms, patients with pulmonary diseases are at elevated risk for experiencing comorbid mental health conditions, including depression and anxiety. Patients with pulmonary diseases tend to report more somatic (rather than cognitive) symptoms of depression including low energy and fatigue, in addition to low mood and decreased interest in pleasurable activities. Common symptoms of anxiety in this population include frequent worry (particularly about health status), restlessness, feeling tense, and panic.

Post-traumatic stress disorder (PTSD) is also more prevalent in patients with some pulmonary diseases, particularly COPD and obstructive sleep apnea (OSA) [33]. Periods of acute dyspnea, a commonly occurring symptom of pulmonary diseases, can be a traumatic event to patients. In turn, dyspnea is associated with hallmark symptoms of PTSD including hypervigilance, avoidance, and increased anxiety [33].

Mental Health Comorbidities in Pulmonary Diseases

When you inquire about his current substance use, you notice a shift in Mr. Smith's facial affect. He smiles for the first time you can remember ever since you were involved in his care. Mr. Smith notes that he has been staying away from "the people, places, and things that get me using." He goes on: "My sponsor has been a rock, and I made a support group meeting every week during the past six months. Sometimes, it feels as if the other meeting attendees are my only support, especially on days when I feel lonely." His smile disappears quickly. "You know, sometimes I don't even think I deserve to go to the meetings and to be treated well. I just feel so guilty about all the things I've done. Now that I am clean, I realize that I can be the grandfather to my grandchildren in ways that I have always wanted. But to do that, I need to get healthier. Do I have any hope? Do you think that I should be allowed to have a relationship with my grandkids, or that it's even worthwhile for me to try?" You see that this patient is really engaged in opioid-cessation treatment, but due to the chronicity of his substance use and ongoing symptoms ofdepression, he lacks confidence and feels incapable of making other significant health changes.

COPD

Mental health symptoms frequently occur in patients diagnosed with COPD. Prevalence of depressive symptoms in COPD patients vary widely from as low as 6% to as high as 60% [34–36]. In a large-scale study of US military Veterans diagnosed with COPD, 80% of Veterans endorsed having symptoms of anxiety and/or depression with 65% of those patients meeting the criteria for a depressive and/or anxiety disorder based on the Diagnostic and Statistical Manual of Mental Disorders, Fourth Edition [34]. COPD patients with higher levels of depression are at increased risk for poor outcomes including higher risk of mortality as compared to their nondepressed counterparts [37]. In fact, there appears to be a positive relationship between mental health symptoms and degree of COPD severity such that patients with more severe COPD symptoms endorse higher levels of mental health symptoms [38]. In addition to increased mood symptoms, patients with COPD have a higher prevalence of tobacco use. In a study of the prevalence of smoking within a large Veterans Affairs Medical Center, patients with COPD had a higher rate of smoking (54%) compared to patients who did not have COPD (39%) [39].

OSA

OSA is associated with elevated risk of a number of mental health comorbidities including depression, anxiety, and PTSD [40]. In a large study of patients receiving care through the Veterans Health Administration, those diagnosed with OSA had significantly higher rates of depression (21.75% vs. 9.43%), anxiety (16.67% vs. 8.39%), and PTSD (11.85% vs. 4.74%) as compared to patients without OSA [41]. A review article examining the prevalence of mental health conditions in patients with OSA found that the median prevalence of depression (48.1%) and PTSD (42.7%) is significantly higher in patients with OSA than prevalence rates of depression and anxiety in the general population [40].

Asthma

Symptoms of depression are more prevalent in patients diagnosed with asthma as compared to the general population with estimates ranging from 30% to 63% of these patients endorsing clinically significant mood symptoms [42, 43]. In a population-based study of over 13,000 German adults between the ages of 18 and 79 years old, having a lifetime diagnosis of severe asthma was associated with an increased likelihood of having a mental health disorder including panic disorder, generalized anxiety disorder, specific phobia, and bipolar disorder [44]. A meta-analysis of 18 population-based surveys of adults across 17 countries found that adults with asthma were 1.6 times more likely to have a depressive disorder, 1.5 times as likely to have an anxiety disorder, and 1.7 times as likely to have an alcohol use disorder as compared to adults without asthma [32]. Tobacco use is also common in patients with asthma with prevalence rates comparable to the general population [45]. This is particularly noteworthy as patients with asthma who actively engage in smoking behaviors have more frequent symptoms of asthma, more severe symptoms of asthma, and are over two times more likely to have asthma attacks as compared to nonsmoking asthma patients [46].

Interstitial Lung Disease

Patients with interstitial lung disease (ILD) score lower on HRQoL measures including physical functioning, psychological well-being, and social functioning as compared to healthy controls [47]. In a prospective study of patients diagnosed with ILD, 23% met criteria for clinically significant depression with dyspnea severity, pain, and sleep quality independently predicting depression severity [48]. ILD is also associated with higher rates of anxiety. In one study examining symptoms of depression and anxiety in patients with ILD, 31% of patients endorsed symptoms of anxiety with 12% of patients meeting criteria for clinically significant anxiety [49]. Theoretical models that explain how depression is maintained in patients with ILD highlight the impact of the disease on functioning and ability to engage in activities [50]. The mechanisms in these models parallel those hypothesized in other pulmonary disorders.

Bronchiectasis

As with other chronic pulmonary diseases, patients with bronchiectasis are at risk for experiencing elevated symptoms of anxiety and depression. In a recent study examining anxiety and depression in patients with noncystic bronchiectasis, the authors found that 21% of patients had symptoms of depression while 40% had symptoms of anxiety [51]. Importantly, symptoms of depression and anxiety have been shown to be associated with reduced HRQoL in this patient population with women reporting lower HRQoL [52]. Unfortunately, there remains a paucity of literature investigating the treatment of mood symptoms in patients with bronchiectasis.

The Relationship Between Self-Efficacy and Mental Health: A Transdiagnostic Factor in the Management of Pulmonary Diseases

Mr. Smith: "It's just so hard to keep living with these symptoms. Every time I have an attack, I have these thoughts like, 'oh boy, here we go again, I can't breathe,' or 'my oxygen is getting low, I'm not going to be able to breathe'. This makes me want to start using again… I just can't seem to shake the anxiety when I can't breathe. The only thing that makes me feel less anxious is a cigarette. Can't I have smoking as my only vice?" The healthcare professional notices that smoking has become a tool in which to regulate his anxiety; however, smoking cessation would also be monumental in improving his dyspnea. You begin thinking about ways in which you could help him improve his confidence around smoking cessation.

A patient's sense of self-efficacy plays a pivotal role in the management of chronic diseases that have a large behavioral component to the management of symptoms [53, 54]. Medications are useless if not taken, the benefits of physical activity are nullified if one is sedentary, and dyspnea will worsen if one does not utilize the exercises learned in pulmonary rehabilitation. In other words, self-efficacy and its downstream behavioral manifestations such as engaging in self-management of chronic disease are essential to patients' well-being. Indeed, mental health symptoms such as low mood, low energy, amotivation, avoidance, decreased interest in pleasurable activities, lack of sleep, and reduced concentration directly and indirectly interfere with self-efficacy.

As with other chronic medical diseases, self-efficacy and its relationship with mental health symptoms have been shown to impact outcomes in chronic pulmonary diseases. For example, in a diverse sample of patients diagnosed with moderate to severe COPD, higher self-efficacy was associated with lower levels of anxiety and depression as well as reduced feelings of breathlessness [55]. A study of older patients with comorbid COPD and depression found that higher levels of self-efficacy predicted better overall functioning above and beyond symptoms of depression as compared to patients with lower levels of self-efficacy [56]. The association between self-efficacy and mood on treatment outcome is further highlighted by the fact that smoking cessation treatment programs have strongly emphasized the importance of a patient's ability to self-manage uncomfortable emotions [57] given relapse risk is high in situations where negative emotions are highly salient [58].

In patients diagnosed with asthma, low levels of self-efficacy have been shown to be associated with a reduced sense of confidence to control asthma and reduced HRQoL [59]. Additionally, self-efficacy has been shown to be associated with continuous positive airway pressure (CPAP) adherence in patients with OSA [60, 61]. COPD patients endorsing symptoms of anxiety and depression report lower levels of energy, increased sense of hopelessness, and heightened frustration with regard to management of their disease [62]. Conversely, COPD patients who receive cognitive-behavioral interventions that include components targeting self-management have a greater sense of mastery and self-efficacy [63]. In a trial of brief cognitive-behavioral therapy with components targeting self-efficacy and distorted beliefs about CPAP use in patients with OSA, patients receiving the active intervention were more adherent to their prescribed CPAP use and endorsed higher levels of self-efficacy as compared to patients receiving treatment as usual [64].

Self-efficacy and mental health symptoms have also been shown to impact risky health behaviors often preceding the diagnosis of a chronic pulmonary disease. In a large-scale study investigating smoking behaviors and depression in Finnish adults, higher levels of depression were associated with lower levels of self-efficacy to quit smoking [65]. Additionally, self-efficacy has been shown to mediate the relationship between mood and treatment outcomes. In a tobacco cessation intervention study, higher levels of depression prior to a smoking cessation treatment program were related to worse outcomes following the program. However, patients who experienced improvements in self-efficacy during the treatment program exhibited better outcomes regardless of pretreatment levels of depression [57]. These studies suggest that self-efficacy can significantly impact primary prevention efforts and be an important construct to target in the development of interventions aimed at improving health behavior in patients with pulmonary diseases.

Mood symptoms can impede a patient's ability to engage in behaviors that help manage their chronic disease. Assessment of these symptoms and providing targeted interventions to help improve patients' sense of self-efficacy and mastery is a vital component in improving learning and behavior for pulmonary patients. A comprehensive review of cognitive-behavioral interventions for anxiety and depression in pulmonary diseases can be found in Chap. 7 of this book.

What Maintains Mental Health Symptoms in Pulmonary Patients?

Given the high rates of comorbid mental health symptoms and pulmonary disease, a growing body of literature has examined different theoretical pathways specific to pulmonary patients that maintain these symptoms. One of the most studied theoretical pathways in pulmonary patients, particularly those with COPD and lung cancer, is the panic/anxiety–-dyspnea cycle [66–68]. Based on cognitive-behavioral theory of panic [69], patients fall into a repetitive cycle in which shortness of breath becomes associated with maladaptive cognitions such as fear of death and loss of sense of control, which then lead to experiences of anxiety and panic (Fig. 5.1).

Another mechanism that may maintain mental health symptoms in pulmonary patients is a sense of loss of control over the illness [70, 71]. Patients suffering from pulmonary disease may feel their illness restricts their ability to engage in pleasurable activities, reducing their experience of rewarding behavior and sense of mastery. Loss of control has also been implicated in low rates of adherence to treatment in

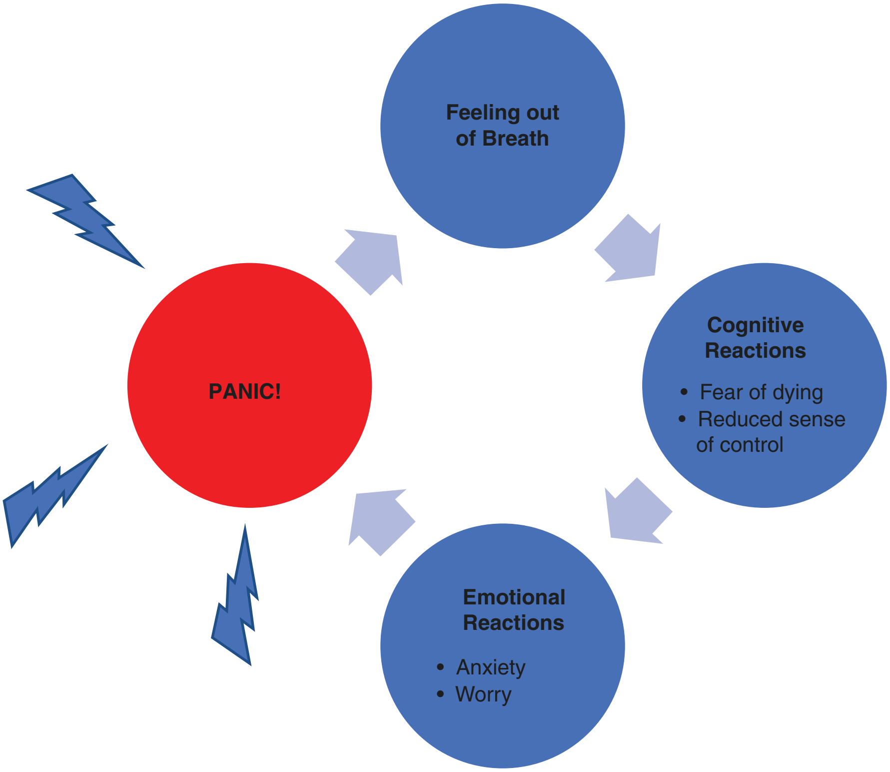

Fig. 5.1 Fear–Dyspnea cycle

pulmonary diseases including COPD and OSA [72, 73]. Ultimately, loss of a sense of control and ongoing anxiety/panic likely reduce patients' sense of self-efficacy.

Applying Theory to Practice: Management of Patients with Comorbid Pulmonary Diseases and Mental Health Conditions

As you review your notes from today's appointment and double-check his labs, you are understandably concerned with the way that Mr. Smith has been managing his COPD. After all, this is a chronic condition that will only worsen if he continues to ignore your instructions. You sympathize with the challenges he faces on a day-to-day basis but also are troubled that he continues to smoke, skips his pulmonary rehabilitation visits, and reports poor medication adherence. His behavior appears counterintuitive, and after all, you have had numerous discussions about how his decisions are directly impacting his health and longevity. Why does he continue to act this way? Possibly this patient endorses some fatalistic beliefs, such as "Nothing I can do will get rid of COPD. I may as well keep smoking." You think to yourself that Mr. Smith's perceived low self-efficacy results in his believing that he is very incapable of quitting smoking. You also recall his family history of having negative experiences in healthcare settings.

Addressing Factors Impacting the Development of Self-Efficacy in Patients with Comorbid Mental Health Conditions

Managing chronic pulmonary diseases, especially in patients with comorbid mental health and substance use disorders, requires a great deal of commitment from the patient. Understanding how self-efficacy is enhanced or reduced may enable healthcare professionals to promote self-management within their patients.

Theoretical models of self-efficacy identify four main sources that lay the groundwork for how to conceptualize patients' confidence to engage in adaptive health behaviors [7]. Understanding these sources of self-efficacy can help healthcare professionals increase a patient's sense of self-efficacy. The first source, and what is considered the most robust source of self-efficacy, is **enactive mastery experience** [9]. Patients feel more confident in their ability to attain certain accomplishments if they have previous positive experiences that they can reflect and build upon. The second main source is **vicarious experience**. Observing similar individuals effectively engage in tasks required for successful management of their condition serves as an example for patients to engage in their own health behaviors. Third is **verbal encouragement**, when another individual provides cues and/or advice to a patient to assist him/her with goal attainment. Notably, perceived experts (i.e., physicians, nurses, respiratory therapists, physical therapists, and other healthcare professionals involved in patient care) are quite effective in enhancing self-efficacy via verbal encouragement because of the inherent credibility in their profession [74]. Lastly, **physiological or emotional arousal** related to engaging in target behavior (i.e., self-management tasks) can alter efficacy expectations, such that positive emotions are related to greater levels of self-efficacy. This is why addressing mental health concerns is integral to improving self-efficacy. Keeping all of these sources in mind will allow healthcare professionals to tailor treatments to their patients' unique needs [75]. Table 5.2 provides clinical examples of each of the four sources of self-efficacy.

Healthcare professionals are an important source of self-efficacy because they are experts in their patients' diseases. Patients who are struggling with meeting the demands of their treatment plan should receive verbal encouragement by way of education and gentle advice from their healthcare professionals in order to build a foundation of treatment-related self-efficacy beliefs. For example, if a patient has been skipping their pulmonary rehabilitation, their healthcare professional can validate that managing a chronic illness is difficult and simultaneously highlight the patient's ability to attend the current visit. Emphasizing that chronic illness management is a "marathon, not a sprint" and reinforcing any and all positive steps in disease management can improve self-efficacy.

Bolstering self-efficacy does not end with simply providing advice. Healthcare professionals can also help patients develop mastery during appointments. For example, if a patient with COPD reports minimal utilization of breathing techniques, spending a few moments practicing with them can help patients learn that they have the capacity to complete tasks that are being asked of them. Developing "SMART" goals (i.e., Specific, Measurable, Action-oriented, Realistic, and Time-limited) collaboratively with patients and ensuring regular follow-up on progress can increase the likelihood that enactive mastery is accomplished [76]. Table 5.3 depicts an example of a completed "SMART" goal worksheet.

Healthcare professionals should also recognize the power of vicarious experience as a pathway to enhanced self-efficacy. Referrals to support groups or therapy classes that include opportunities for additional contact with fellow patients (e.g., pulmonary

Table 5.2 Sources of self-efficacy

Source of self-efficacy	Clinical example
Sense of mastery	Patients with OSA successfully uses their CPAP during the day to help their body adapt to using the machine at night.
Vicarious experience	Patient attends group pulmonary rehabilitation classes and witnesses how other members of the group increased their ability to walk longer distances with less dyspnea after daily practice.
Verbal encouragement	Healthcare professional expresses hope in their patient's ability to stop smoking when recounting a story of their former patient. They recalled that their former patient smoked twice as much and had successfully quit by using the nicotine replacement patches and gum and attending the tobacco cessation classes the hospital offers.
Physiological/ emotional arousal	Patient with asthma reminds herself that her wheezing is time-limited, and using her medications as prescribed and practicing controlled breathing will help her stay calm and limit the intensity of symptoms.

Table 5.3 Example SMART goal worksheet using Mr. Smith's case vignette

Specific	I will walk around the block two times each morning before breakfast for two weeks.
Measurable	Yes! I live in the city and can easily track when I have completed two blocks.
Action-oriented	Yes! I will be engaging in active exercise.
Realistic	Yes! Last week I started walking around the block once each morning and was successful.
Time-limited	Yes! I will do this for the next 2 weeks and then re-evaluate to see if I am prepared to increase the distance.

rehabilitation, smoking cessation groups, and pulmonary fibrosis support groups) provide social learning opportunities with others who understand their disease's challenges most intimately. Additionally, healthcare professionals should consider obtaining and/or developing resources that demonstrate patients engaging in requisite health behaviors. For example, if a patient is struggling with adherence to their CPAP machine, their healthcare professional can provide them with a link to a YouTube tutorial that demonstrates patients (even celebrities!) discussing their experience with CPAP machine use and how they have successfully adhered to their treatment recommendations.

Lastly, emotional and physiological arousal can decrease self-efficacy if a patient feels anxious, scared, or intimidated when attempting to engage in a requisite management task. If a patient is struggling to meet a treatment goal, inquiring about barriers to completing this task is helpful. In particular, "When I bring up [specified treatment goal], what comes to mind? What do you feel?" These simple questions often provide insight into the patient's specific concerns, which opens the door for a discussion of how to mitigate the problem and decrease the emotional response. This approach may work well for a number of patients. However, patients with comorbid depression and anxiety often experience symptoms that interfere with task engagement, such as decreased interest/pleasure in activities, fear/avoidance of engagement in activities that may trigger physiological symptoms, and withdrawal from adaptive social networks [77].

Introducing Concerns About Mental Health to Patients

Before you conclude your appointment with Mr. Smith, you recall that he completed mental health questionnaires that have become a new part of the regular pre-appointment process. You review the total scores and see that he endorsed moderately severe symptoms of depression and moderate symptoms of anxiety. He also endorsed high nicotine dependence. You begin to put the pieces together and believe that a combination of fatalistic beliefs related to his health and his mental health symptoms are contributing to poor treatment adherence. You recognize that he wants to live a better, healthier life, but feels doomed to an illness that "cannot be changed." If you can support him in feeling more confident, he may be more *successful in making changes to improve his health and feel better. You shift your stance and decide to initiate a conversation about mental health care rather than focusing on how the long-term consequences of his poor adherence will only make things worse.*

Healthcare professionals in pulmonary settings are in an optimal position to provide their patients with education about and referrals for mental health care, as management of a chronic pulmonary disease requires a long-term relationship between patient and healthcare professional. However, some non-mental healthcare professionals feel that having these discussions is outside of their scope of practice or feel uncomfortable or limited in their knowledge of mental health concerns [78]. The following strategies can help facilitate conversations about mental health.

1. *Addressing mental health is a part of a pulmonary patient's treatment plan*: A helpful way to introduce the topic of mental health concerns is to briefly inform the patient that, as a healthcare professional, you are aware of the many different components that go into their care (e.g., taking medication, making appointments, exercising, and family obligations), and that another important factor of one's overall health is enhancing one's mental health. Consistent with the spirit of motivational interviewing (which is reviewed in detail in Chap. 6 of this book), you can ask permission to speak with the patient about mental health symptoms [79]. By introducing the topic in this manner, you are respecting their autonomy and consciously shifting the focus of the visit to their mental health.
2. *Normalizing and empathizing*: Next, patients may benefit from learning about how commonplace mental health symptoms are in pulmonary populations, helping to contextualize their experiences. Even vaguely referencing other patients who have struggled with depression can be an effective way to educate patients and validate their experience [80]. Openly expressing that you are worried about how their mental health is not only impacting their health, but their overall HRQoL can allow for a collaborative discussion about seeking specialized treatment.
3. *Providing information*: The Substance Abuse and Mental Health Services Administration and the National Institute of Mental Health have free, evidence-based resources that describe various mental illnesses [81, 82]. Having these brochures and handouts in your office not only demonstrates to your patients that you value their access to mental health care but destigmatizes and normalizes the referral to mental health.
4. *Confirming the referral*: Lastly, recommending a mental healthcare professional and instilling hope is an effective way to conclude this discussion. Like all healthcare decisions, the patient ultimately decides whether or not he/she will accept or decline a specialty referral. Some patients will simply decline any referral to mental health treatment. In the spirit of respecting their autonomy, while also ensuring that they are adequately informed of available and recommended care, it can be useful to ask permission to address mental health concerns at future visits if they decline a referral at the current visit. In our experience, most patients are willing to have these conversations in the future, even if they have doubts that they will be more open at that time.

Additional Recommendations for Practice

Screening Implementing regular screening for mental health conditions is strongly recommended. A number of the screening measures reviewed in Chap. 7 of this book are self-reported, have low participant and healthcare professional burden, and can be completed immediately prior to healthcare appointments in the waiting room. In addition, reliable and validated cultural scales should be considered a vital part of the screening process so that healthcare professionals can further identify what factors may contribute to behavior change [13]. Simply requesting that patients complete these measures on an annual basis can increase the likelihood that mental health disorders are discovered [83]. In our experience, patients are accustomed to completing forms prior to medical visits and usually are comfortable completing mental health questionnaires. Administrative staff can be trained to score these measures and flag healthcare professionals if patients have screened positive; therefore, healthcare professionals are alerted ahead of time and can prepare to have a discussion about mental health during the visit. Additionally, monitoring patients' response to mental health screeners can be tracked over time, which allows for healthcare professionals to recognize changes in symptoms. Furthermore, screening for mental health conditions facilitates important conversations related to patients' mental health without significantly taking time away from other relevant health problems [84].

Screening measures only provide initial information about an individual's psychological status and further assessment would be needed in order to make definitive diagnoses. Self-reported measures should assist but not be the sole tool to refer patients to higher levels of mental health care. Patients' subjective reports of mood and healthcare professional observation of the patient's mental status can also signify that a patient may benefit from a referral to a mental health professional.

Use of Interdisciplinary Treatment Teams We strongly recommend the use of interdisciplinary teamwork for treating patients with pulmonary diseases, such as the primary care-mental health integration model being implemented nationally across the Veterans Health Administration [85]. Interdisciplinary treatment teams offer same-day access to mental healthcare professionals and further supports the idea that chronic pulmonary diseases are multifaceted and are best treated by a multidisciplinary team of healthcare professionals including physicians, nurses, physical therapists/physiotherapists, respiratory therapists, and mental health experts.

Conclusion/Summary

You ask Mr. Smith's permission if you could have a conversation with him about his psychological well-being. You inform him that you are concerned about him as a person and want to assist him in any way possible (verbal encouragement). *When you ask if he would like assistance to improve his mood and stop smoking, he looks* *directly into your eyes and states, "Please." You provide him with brochures about depression, anxiety, and tobacco cessation groups, which he gladly accepts* (opportunities for vicarious learning). *You develop an attainable "SMART" goal with Mr. Smith that he rates both as highly important and confident that he can accomplish in two weeks; you want him to increase his self-efficacy in the management of his illness. Thoughtfully utilizing the SMART goal method assists in your aims to do so* (increasing sense of mastery)*: He will cut down his daily smoking by 20% and will attend his intake session with the hospital's psychiatrist. You establish your follow-up appointment, and he thanks you before leaving.*

Previous research has widely supported the role of self-efficacy in health behavior change. Understanding the impact *both* sociocultural and mental health factors may have on the successful self-management of chronic pulmonary diseases is a vital component of supporting this patient population. Healthcare professionals working with this population may effect positive behavior change by implementing some of the strategies reviewed in this chapter including understanding the context in which patients view their health (e.g., shared beliefs, personal beliefs, and fatalism) and their mental health status. We hope the empirical evidence presented supports clinical care that considers multiple patient-specific factors, strengthens patient–healthcare professional relationships, and provides a framework to collaboratively foster health behaviors that improve physical and mental health among this complex patient population.

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Chapter 6
Integrating Motivational Interviewing into Pulmonary Healthcare

Arpi Minassian and Neal M. Doran

Overview

Making changes in health behavior can be difficult for almost everyone. Most people are aware of the benefits of behavior changes such as quitting smoking, losing weight, or exercising more. However, simply possessing the knowledge is typically not enough to influence change, be it ceasing unhealthy behaviors, beginning healthy ones, or maintaining positive behavior changes. People with pulmonary disease are no exception and may feel especially challenged to make changes because the very symptoms of their disease negatively impact virtually all of their daily activities. For example, the majority of smokers with pulmonary disease will agree with their healthcare professionals that they should quit. Most participants in a pulmonary rehabilitation program experience the positive effects of physical exercise and know that they should continue exercising after the completion of the program. Because many of these patients struggle with actually implementing such health behavior changes, motivational interviewing (MI), an empirically supported communication style, is an optimal approach to assist people with pulmonary disease clarify and resolve their ambivalence about effecting behavior change.

In this chapter, we introduce MI and briefly describe its development and initial applications. The theoretical concepts that underlie MI will be reviewed, as will specific interview and interaction techniques. A brief review of its efficacy for health conditions, including pulmonary disease, will be presented. We will offer guidance

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on integration of MI into the care of patients with pulmonary disease, in both traditional one-on-one and group settings. Hypothetical case examples will be provided to offer the reader practical exemplars of the implementation of MI theory as well as its actual practice. While the responsible practice of MI does require training, ongoing proctoring, and institutional support, it is hoped that this chapter will provide a starting point for healthcare professionals from multiple disciplines, including physicians, nurses, physical therapists, and respiratory therapists (RTs), who are interested in incorporating this approach into the care of their patients.

History and Initial Applications of MI

MI was developed by William Miller and colleagues. The original impetus occurred during a trial of behavioral treatment for alcohol misuse. Study therapists had been trained to demonstrate empathy [61], consistent with person-centered models of psychotherapy [84]. The researchers were surprised to find that therapist empathy accounted for substantial proportions of the variance in drinking outcomes as much as 2 years later [57]. These observations, combined with his experiences working with a group of psychologists in a Norwegian alcohol treatment center, led to Miller's efforts to integrate behavior therapy with a person-centered approach, and subsequently to MI [56].

At this time, addiction counselors tended to use a confrontational style that actually increased resistance to change. Counselors instructed clients to quit in ways that varied from honest feedback (e.g., "You must quit, drinking is ruining your life") to loud, profane denunciations (e.g., "Shut up and listen…alcoholics are liars, so we don't want to hear what you have to say") [97]. This observation was consistent with self-perception theory, which suggests that confrontation entrenches the client in his or her pre-existing position [5]. In contrast, an empathic, client-centered style can increase motivation to change. In MI, the clinician takes an approach that recognizes that change is difficult, and sets out to work through the reasons for and against change. The clinician explores the client's reasons for change by using reflective listening, by which the client hears him or herself argue *for* change, rather than against. Client statements arguing for change are referred to as "change talk" (Table 6.1). Eliciting change talk is an important goal of MI because change talk increases the client's commitment to making positive changes, and has been

Table 6.1 Change talk types and examples

Desire to change	I wish I could find a way to start an exercise program but it's so hard to keep it up.
Ability to change	I was better at eating healthy before my spouse got sick.
Reason to change	My son won't let the grandkids come over until I stop smoking.
Need to change	Things aren't going well – something's got to give.

associated with better behavioral outcomes [34, 36, 95]. MI is directive, as the clinician uses reflective listening and other techniques to elicit client change talk, thereby strengthening the client's motivation for change [60]. One method that an MI interviewer uses to increase change talk and motivation for change is developing discrepancy. Discrepancy refers to the strategic use of reflections and other statements intended to focus the client's attention on the gap between the client's personal values and the current state [14]. For example, the interviewer may use reflection to bring the client's attention to the fact that continuing to smoke following a heart attack is at odds with his strong desire to see his grandchildren grow up.

Having developed an initial conceptualization of MI, Miller and others proceeded to test it as the basis for intervention. MI was originally viewed as a way to enhance motivation prior to treatment [60]. However, findings from early trials indicated that brief MI-based interventions tended to be effective in and of themselves and that a confrontational clinical style engendered resistance and poor treatment outcomes [58, 66]. Findings from early trials indicated that clients who received a single MI session prior to treatment had better abstinence outcomes, were more likely to stay in treatment, and had greater motivation to change [8, 13, 65].

In 1989, Miller began a collaboration with Stephen Rollnick, yielding a new focus on ambivalence [62]. Changing maladaptive behaviors typically involves forgoing longstanding, immediately reinforcing behavior in favor of a new pattern that reduces long-term risk for negative outcomes. This naturally produces ambivalence. In MI, the role of the clinician is to acknowledge and normalize this ambivalence, and to help the client understand it. Exploring ambivalence provides the interviewer with opportunities to elicit internal motivations for change [60]. Importantly, the clinician's job is to help the client generate statements about reasons for changing. The MI clinician assiduously avoids statements that could be perceived as arguing or advocating for change, because these tend to yield resistance and reduce the likelihood of change [12, 75]. As Bem noted, people are more responsive to their own arguments than to others' [5]. Relatedly, when a client expresses resistance to change, the clinician perceives it as a natural part of working toward change. Rather than arguing, the clinician "rolls with the resistance" by using reflective listening, developing discrepancy, and exploring the reasons for resistance.

MI Principles and Techniques

Those of us who have gone into professions dedicated to helping others to reduce or cope with physical or psychological symptoms may tend to view change as the result of the services that we and our colleagues provide. However, it is increasingly clear that most people who change successfully do so on their own [41, 42, 90]. Thus, treatment may be better conceptualized as a means of facilitating the natural process of change, particularly for those who are struggling. MI is designed to accomplish this by enabling the client and the interviewer to collaboratively work through ambivalence, increasing the client's motivation to change.

Table 6.2 Motivational Interviewing Principles

Expressing empathy	Communicate respect, understanding, acceptance of clients' unique feelings, values, and perspectives
Developing discrepancy	Focus clients' attention on the difference between current behavior and values or hopes for the future
Rolling with resistance	A signal to change direction or respond in a new way to take advantage of the situation without confronting
Supporting self-efficacy	Recognize clients' strengths and bring them to the fore whenever possible

MI has four basic principles that guide the clinician: expressing empathy, developing discrepancy, rolling with resistance, and supporting self-efficacy [63] (Table 6.2). Relatedly, MI experts have emphasized the "spirit" of MI, which is viewed as more important to client outcomes than any specific techniques [2, 68]. Elements of the MI spirit include collaboration, supporting the client's autonomy to make his or her own choices, and evoking rather than demanding change talk [62]. Other interventions designed to help clients make behavior changes tend to be focused on how to accomplish the desired changes. In contrast, MI focuses on using the client–healthcare professional relationship to help the client to make the decision to change, or to strengthen motivation or resolve to do so [69]. A number of studies have supported the hypothesis that this approach yields better client outcomes [9, 17, 31, 72].

MI makes several assumptions. First is that all clients have a powerful drive toward healthy, adaptive behavior. This drive fluctuates over time and can be influenced in treatment. A second assumption is that, while the healthcare professional has useful knowledge to share, the client knows best how to change his or her circumstances. Importantly, attempting to motivate the still-ambivalent client via advice, education, persuasion, logic, or warnings is likely to generate resistance. Finally, the healthcare professional assumes that the client's decision to change and to work toward that change is a critical ingredient to successful change [69].

A common misconception is that MI is directly related to the transtheoretical model (TTM) of change [78], which includes a focus on clients' readiness to change. The TTM identifies specific stages of change (pre-contemplation, contemplation, preparation, action, maintenance, relapse, and recycle), each with a common set of thoughts and behaviors. The TTM was novel in advocating that therapists work to increase the motivation of clients not yet ready for change, and MI was a natural fit for this role; in turn, the stages of change provide a straightforward way to conceptualize the potential role of MI in helping clients move from considering changes to actively working toward them [64].

MI can be thought of as occurring in two phases. In the first, motivation-building phase of MI, the clinician focuses on building motivation for change. Motivation rests on the extent to which the client feels willing, able, and ready to change. In MI, willingness is sometimes conceptualized as the extent to which the client perceives a particular change as important, and ability as the client's confidence to effect change. A common MI technique is to ask the client to rate importance and confidence on a 0–10 scale, also known as a readiness ruler, to help guide the focus of this phase. For a client with room for improvement in both importance and confidence, it may be beneficial to focus initially on confidence (e.g., if the client has been unsuccessful in prior change attempts), but this will be client dependent. These ratings can help the healthcare professional understand the client's motivation and determine the initial targets of treatment. Subsequent exploration of ambivalence can focus on developing discrepancy between the client's current and ideal states (e.g., "It sounds like one concern you have about smoking is that it makes it harder to be the parent you want to be.").

During the motivation-building phase of MI, five specific behaviors are recommended [63, 64]. The first four are included in the acronym *OARS: open-ended questions, affirmations, reflections, and summaries*. While these techniques are not unique to MI, in MI they are used explicitly to explore a client's ambivalence and to increase his or her motivation to change. The goal is to build a collaborative relationship, to encourage the client to be expressive, and to explore ambivalence. *Open-ended questions* facilitate this goal by encouraging greater expression from the client. For some clients, simple open-ended questions (e.g., "What brought you here today?") are sufficient to start the conversation. Others may start out less comfortable with expression or, if they have greater ambivalence, may have a harder time discussing reasons for change. In such cases, it may be useful to ask them to express both sides of the issue (e.g., "What are the good things about smoking? What benefits do you get from it?" followed by "And what about the other side – what concerns do you have about smoking?"). Some guidelines to consider include that the client should be talking more often than the healthcare professional, and that the healthcare professional should not ask more than two questions consecutively. Instead, after an open-ended question, the healthcare professional should use the other elements of OARS to explore the client's thoughts about the positive and negative aspects of change.

The second element of OARS is directly *affirming* the client. The healthcare professional may express appreciation of the client coming to treatment, or the effort that it took to talk about concerns, or the coping skills that have been required to deal with a difficult situation. Affirmations help to build rapport and reinforce the idea of mutually exploring the possibility of change.

Reflective listening is perhaps the most important element of MI Crucially, reflections encompass not only listening attentively, but also responding appropriately. A series of inappropriate ways of responding, termed "roadblocks," have been identified [35] (Table 6.3). The term roadblocks is used because this kind of communication can be obstructive and may cause the client to change direction and be resistant. Roadblocks are inconsistent with the spirit of MI. Examples include ordering or commanding, warning or threatening, giving advice, providing solutions, arguing or persuading, criticizing or blaming, shaming or ridiculing, interpreting or analyzing, approving or praising, and sympathizing or consoling. Roadblocks tend to imply an unequal relationship between the client and an expert, which undermines the collaborative spirit of MI. They also redirect the client away from examining ambivalence.

What does reflective listening look like? The goal is to indicate that the healthcare professional hears and understands what the client is communicating. The

Table 6.3 Roadblocks – communication styles to avoid

Ordering or commanding	Criticizing or blaming
Warning or threatening	Shaming or ridiculing
Giving advice or solutions	Interpreting or analyzing
Questioning or probing	Approving or praising
Arguing or persuading	Sympathizing or consoling

healthcare professional takes a reasonable guess at the intended meaning and expresses it as a statement, rather than a question. The distinction is important, as a question may be more likely to generate resistance. The statement's purpose is to check its accuracy with the client, and to keep the client moving toward change talk. Simple reflections may repeat a portion of the client's statement, while deeper reflections may guess at the emotion the client is feeling or "continue the paragraph" by reflecting the statement the client may make next. Deeper reflections tend to be more effective but are also a function of the healthcare professional's experience. It is important to note that reflective listening is directive. The healthcare professional is choosing which statements to follow up on. After asking an open question, the healthcare professional should respond to the client's answers with reflective listening, with the goal of eliciting change talk. Healthcare professionals with strong MI skills will typically reflect 2–3 times more often than they ask questions. The case vignette outlined later in this chapter illustrates the frequent use of reflections.

The final component of OARS is *summarizing*. Summary statements bring together and reinforce multiple points of discussion. For example: "It sounds like you're worried about the impact smoking is having on your life. Because you're not breathing as well it's hard to be active, and to be the grandparent you want to be. You're also concerned it could lead to bigger problems that would force you to retire, creating a financial burden for your family. What else?" Summaries send the message that the healthcare professional has been listening. Some are brief and intended to continue the client's momentum. Others may link a current discussion to an earlier discussion, particularly with an eye toward clarifying ambivalence. Finally, transitional summaries are intended to shift focus to the next topic, either between sessions or between MI phases.

The fifth MI skill is *eliciting change talk*, which is explicitly a directive method for resolving ambivalence utilizing OARS. The healthcare professional seeks to have the client make the argument for change [56]. The primary categories of change talk are the advantages of changing, the disadvantages of not changing, optimism about the ability to change, and expressions of intent to change. The more statements the client makes that fall into these categories, the more likely she or he is to change. A healthcare professional may use client ratings of importance and confidence as a starting point. If a client rates her confidence as 3 out of 10, the healthcare professional may ask "Why 3 and not 0?" "What would it take for you to move from 3 to 8?" Most of the time, a client's responses to such questions will take the form of change talk. It can also be helpful to make a list of the pros and cons of changing and of not changing. This provides a picture of the client's ambivalence that can be explored. Another method for eliciting change talk is asking a client to imagine the worst possible consequences of not changing, or the best possible consequences of change – e.g., “Imagine that you decide not to make any changes – what are the worst things that might happen?” Or “Imagine that you were able to make this change successfully. How might things go differently for you?” Discussing how things were different before the current problem began, or how they might change if it can be resolved, can also be helpful ways to induce change talk. The latter approach may also fit well with discussing a client’s goals and values, and how they are or are not consistent with current behavior. To the extent that behavior seems to be inconsistent with deeply held values, such a discussion provides the healthcare professional with an opportunity to explore and increase motivation for change by developing discrepancy. Table 6.4 summarizes the MI skills relevant to the motivation-building phase of MI.

In the second, strengthening phase of MI, the focus shifts to bolstering the client’s commitment to change. This phase begins when the client feels willing to make changes and confident that he or she can do so. Signs of this readiness include lessening resistance and increased change talk, envisioning the future after making a change, and questions about change in place of questions about the existing problem area [63]. In this phase, the main task is to keep the client pointed toward change. This phase is often – though not always – easier than the first. Nevertheless, this second phase includes some problems to avoid. The first is assuming that all ambivalence has been resolved. The second is overprescribing, or recommending a plan that the client does not agree with. The final potential problem is not providing enough help. All of these problems risk increasing ambivalence and resistance, and decreasing motivation to change. So how should the healthcare professional approach the second phase?

A good first step is to recap progress to date, including initial problems and concerns, ambivalence, and client statements about the importance of change and his or her confidence in changing. A recap can be followed by a key question, which is an open question that elicits the client’s plans. The goal is to get the client to think and talk about next steps (e.g., “What do you think is next for you here?”). The client’s response should be met with reflections to clarify his or her thoughts and plans, and to respond appropriately to change talk and to resistance. At this point, the healthcare professional may also give some advice, sharing his or her expertise, while taking care to only do so after understanding the client’s thoughts and knowledge and when the client has requested it or given permission. From these steps, the client and the healthcare professional can collaborate on a plan for

Table 6.4 MI Skills

Open-ended questions	Encourage greater expression from the client
Affirming	Rapport-building and reinforce intent to work collaboratively toward change
Reflective listening	Statements indicating the client has been heard and understood
Summarizing	Reinforce multiple elements of discussion, often including pros and cons of change
Eliciting change talk	Client expresses desire, ability, reasons, and/or need for change

enacting change. This generally includes four steps: setting goals, considering options for change, developing a plan, and eliciting commitment to change. During this part of the process, it is important for the healthcare professional to help the client to set goals and make plans that are realistic and client-determined. Imposing the healthcare professional's goals is likely to backfire. The extent to which plans are realistic or advisable can be determined collaboratively, by asking the client to give a confidence rating, or discussing potential consequences. After collaborative development of a change plan, the healthcare professional may use a summary of the plan that includes goals, needs, intentions, and beliefs. The next step is to elicit commitment from the client, often by directly asking, "Is this what you want to do?" If the client is not ready to do so, the healthcare professional should return to OARS techniques to explore and resolve this ambivalence.

Resistance to change is common, in either phase of MI. Resistance tends to be reflected in either "sustain talk" or statements that favor not making changes, or in discord, which is a disruption of the therapeutic relationship. There are two general approaches to responding to resistance, both of which can be useful. The first approach consists of different types of reflections. The first is a simple reflection acknowledging the client's perception or feeling. This allows for exploration of the feeling and maintains the collaborative spirit of MI. A second type is amplified reflection, which is intentionally exaggerated beyond the client's meaning (e.g., "So you may have gotten a DUI, but that was just bad luck. Your drinking hasn't caused you any problems"). The case vignette later in this chapter contains another example of an amplified reflection. If an amplified reflection works, it will encourage the client to backtrack and engage in change talk. Importantly, the amplified reflection must be done empathically and without sarcasm to avoid sounding hostile. Finally, the healthcare professional may use a double-sided reflection that expresses both sides of ambivalence; for example, "You do think that you will feel better if you used your CPAP machine and at the same time you know it will be really difficult and disruptive." The second approach consists of different ways of refocusing the client. These include temporarily moving toward a less difficult issue; reframing (e.g., conceptualizing repeated unsuccessful efforts as perseverance); and agreeing with a twist. The latter consists of initially reflecting and then reframing the client's statement.

It is important to recognize that resistance is normal and not a sign of pathology. In fact, resistance offers an important opportunity to the healthcare professsional. The client has likely expressed similar resistance before, internally and/or with others. The client may expect the healthcare professional to argue against resistance, playing the same role that others have done in the past. The healthcare professional who avoids this path increases the odds of a different outcome [63].

Efficacy Studies

More than 500 controlled trials of MI have been published in the past 40 years, across a variety of clinical concerns [60] as well as several meta-analyses [14, 45, 50, 53, 73, 85]. MI has generally been found to have a modest effect in addressing problems including alcohol, tobacco, and other substance use [46, 49, 87], behavioral concerns such as problem gambling [98], and other problematic health behaviors [10, 18, 20, 33, 37, 55].

In addition to clinical trials, the hypothesized mechanisms in MI have been subject to a number of process-oriented studies. It has been posited that MI consists of two primary mechanisms: the "spirit" component (e.g., accurate empathy, collaboration, and respect for the client's autonomy) and the technical component (e.g., using reflections to elicit change talk). The latter has received greater attention in the literature. First, it has been shown that a healthcare professional's use of MI techniques yields client change talk, and that this effect can be reversed by the use of behaviors that would be expected to increase resistance [32]. Multiple other studies have confirmed that interviewers with better MI skills will produce both the frequency and the strength of clients' change talk, and conversely that behaviors that are frowned upon in MI increase sustain talk [11, 29, 38, 54]. Importantly, data also suggest that when clients engage in more change talk relative to sustain talk, they are more likely to change behavior [16, 30, 38, 67, 95].

While studies of the active ingredients of MI have generally focused on the use of specific techniques, evocation of change talk and subsequent outcomes, there is also indirect evidence for the importance of the MI spirit. For example, the efficacy of MI has varied across sites in multisite trials [4], and across healthcare professionals within individual trials [79]. Interestingly, one MI meta-analysis found that MI was more effective in trials that did not use therapist manuals [36]. These findings suggest that variables that are sometimes referred to as "common" or "nonspecific" factors that are clinician- but not therapy-specific but are a focus of MI (e.g., empathy, client-centered interpersonal skills), play an important role in determining clinical outcomes [59, 70, 71, 92].

MI Applications in Pulmonary Disease

Smoking Cessation (See Chap. 14)

There are a number of behaviors relevant to pulmonary disease that can be targets for an MI approach. Probably the most robust body of literature on the efficacy of MI, not specific to the pulmonary disease population, is focused on smoking cessation. A meta-analysis of 28 studies and 16,000 participants revealed that MI approaches do have positive, albeit modest, effects on likelihood of abstinence from smoking for at least 6 months [49], with a reliable advantage of MI over usual care or brief advice. Interestingly, trials that implemented brief sessions of MI, e.g., 20 minutes or less, reported effect sizes that were as good as or better than those with longer sessions. This finding suggests that the efficacy of MI does not hinge on lengthy and repeated sessions; rather even brief conversations using MI concepts in the course of usual contact with patients may be helpful. Thus, we advocate for a truly "integrative" approach to using MI with patient populations where healthcare professionals, which we define broadly here to include physicians, nurses, RTs, and others, can implement the techniques reviewed above whenever an opportunity arises to discuss behavior change with their patients. The case vignette presented later exemplifies such an opportunity.

MI for smoking cessation in patients either with or at high risk for pulmonary disease has been investigated, with generally positive effects. For example, a telephone-based series of MI counseling sessions (up to six sessions) resulted in higher quit rates than usual care for a group of patients at risk for lung cancer [89]. In another study, smokers consulting a pulmonologist received in-person MI from the healthcare professional, alone or in conjunction with pharmacotherapy; findings indicated that smoking prevalence decreased regardless of whether pharmacotherapy was provided [48].

There are challenges to implementing MI in smokers with pulmonary disease who are driven by concerns and beliefs unique to this population. These factors were described in a small qualitative study of smokers with chronic obstructive pulmonary disease (COPD) who were interviewed about their beliefs related to smoking and quitting [51]. Distinct themes were identified such as fear of not being able to quit and thus becoming ill and hospitalized, feeling criticized by others including healthcare professionals for not being able to quit, hiding their smoking from loved ones and healthcare professionals, and avoiding frightening health information, e.g., not wanting to partake in lung function tests or other evaluations. Flott [28] directly relates suggested strategies for smoking cessation to the patient's stage of change. For example, for a patient still deciding whether to change, which can be characterized as the contemplation stage of change, the healthcare professional should address potential misconceptions about smoking, one of which may be that, since the individual already has lung disease, “the damage is done” and quitting smoking will not help. Another common misconception among smokers with pulmonary disease is that there is a “safe” amount of cigarettes they can smoke. Again, such patients may be in the contemplation stage since they are considering some kind of behavior change, e.g., cutting down the quantity of cigarettes they are smoking. For a patient who has quit or cut down smoking and is continuing to work toward achieving or maintaining abstinence (action stage of change), a review of the improvement in symptoms may help reinforce behavior change. These strategies can be used in conjunction with MI to enhance motivation. These studies provide very useful information about features unique to patients with pulmonary disease who continue to smoke. In order to maximize the benefits of an MI approach, healthcare professionals are advised to listen for and even introduce these factors in their work with patients. Such efforts, in combination with more extensive training and ongoing supervision in MI, may more effectively encourage and empower healthcare professionals to use MI strategies with their pulmonary patients.

Physical Exercise (See Chap. 8)

One of the most challenging behaviors to initiate or maintain for people with pulmonary disease is exercise. COPD patients, for example, spend half as much time as healthy people doing physical activities and have more sedentary periods [77, 94]. Dyspnea and fatigue, symptoms present even in mild stages of the disease, substantially lessen motivation to engage in nonsedentary activities, as does the use of supplemental oxygen. There is also a prominent psychological component; 37–71% percent of people with chronic pulmonary disease experience depression [88], which has a direct negative impact on engagement in activities. Unfortunately, as many patients with pulmonary disease will readily attest, the relationship between reduced activity and increased depression is a "vicious cycle," where inactivity worsens mood, which in turn further drives down the patient's motivation to be active. Substantial evidence, however, indicates that increasing physical activity or at least decreasing sedentary periods is beneficial for people with chronic lung disease, to the point that greater physical activity is the strongest predictor of mortality for COPD patients when many other factors are accounted for [96]. Most people with pulmonary disease acknowledge that engaging in regular physical exercise is challenging but makes them feel better physically and emotionally. This "conundrum" of physical exercise for pulmonary patients and the ambivalence that patients experience when comparing its benefits to its notable challenges create an optimal opportunity for MI approaches.

Not surprisingly then, MI-based interventions to target physical activity have been attempted in patients with pulmonary disease. A small study randomized COPD patients to a control condition or four in-person MI sessions and measured physical activity with a pedometer [21]. Although the patients who received MI did increase their step count more than the controls, with a moderate-to-large effect size, this difference did not reach statistical significance in the small sample. A larger study found similarly modest results such that COPD patients in a pulmonary rehabilitation (PR) program randomly assigned to receive MI as part of their treatment did not spend more time walking, though their levels of moderately intense activity were somewhat greater than that of the control group [15]. Strengths of these studies include objective measures of physical activity (i.e., pedometer/accelerometer), but potential limitations were noted such as likely insufficient MI training of the healthcare professionals (see section on fidelity below) and patients' general lack of adherence to their PR programs. More broadly, a systematic review on the effects of MI on physical activity levels in people with chronic health conditions suggested a modest positive effect of the intervention [73]; however, this meta-analysis did not include findings specific to patients with lung disease. Thus, the question of whether MI can reliably increase physical exercise in the pulmonary population remains unanswered. Fortunately, there are two additional clinical trials in progress. One group [80] is randomizing patients with COPD in a PR program to either treatment as usual or several in-person MI sessions and will track physical activity with ambulatory devices. Another study reportedly in progress [39] will take place at two different hospital sites and randomize COPD patients to either a traditional hospital-based PR program or a home-based program with telephone MI sessions. There is much progress to be made in facilitating physical activity in people with pulmonary disease, and well-designed trials with experienced MI healthcare professionals are vital.

As we await the progression of empirical research, we suggest that healthcare professionals take steps to integrate MI communication techniques into everyday interactions with patients about physical exercise. An open-ended query about recent activity or exercise behavior, followed by simple reflections of the patient's response, is an easy starting point for a potentially fruitful discussion about where the patient is at present versus their personal goals for physical activity. An example of how such a conversation might go is presented later in this chapter.

Self-Management of Disease and HRQoL (See Chap. 11)

Self-management, defined as the patient's own ability to cope with his/her medical condition, is strongly related to better HRQoL in people with chronic lung disease [19]. To that end, Benzo and colleagues [6] have developed an eight-session intervention for patients with COPD that uses MI to communicate with patients about individualized "action plans" that can include strategies for coping with stress and difficult emotions, quitting smoking, breathing more effectively, managing fatigue, increasing physical activity, taking medications, and other personalized goals. Training of clinicians in the intervention techniques is intensive and includes didactics, role playing, and monitoring of skills via videotape and feedback. The authors have also implemented treatment fidelity methodologies. Patient participants reported high satisfaction with treatment and a good working alliance with healthcare professionals, and tended to remain in treatment. Although implementing an individualized program that requires intensive professional training may seem daunting, its potential positive benefits are likely worth the investment. Patients' subjective feedback about the MI-based interventions included an increased sense of self-awareness and accountability, improvement in physical activity and mood, and positive feelings about their relationships with their healthcare professionals [7]. Whether these positive experiences manifest in objective, measurable improvements in health indices is an important next step of investigation. A series of telephone-based MI sessions in people with COPD yielded decreases in self-reported dyspnea and improvements in fatigue and other domains of HRQoL [81], which, despite the lack of a control condition, is a valuable finding especially relevant to patients who cannot access a hospital-based program. An ongoing trial is randomizing patients recently hospitalized for COPD exacerbation or heart failure to either standard of care or an intervention that incorporates in-person and telephone MI-based sessions to encourage self-management strategies [27]. Re-hospitalization rates will be the primary outcome measure, which should have downstream implications for healthcare usage and overall HRQoL.

While much of the work described above has focused on patients with COPD, one study examined post-operative patients with lung cancer [40]. A six-session treatment based on MI principles was compared to treatment as usual in a small group of patients. Positive effects of MI were observed in depression and anxiety symptoms, self-efficacy, and HRQoL measures, although lung function did not differ from controls. This study adds to a body of literature suggesting that MI interventions have promise in improving patients' subjective experience, including their sense of autonomy and control over certain aspects of their diseases, which even in the absence of objective changes in health status can have a powerful and personally meaningful impact for individuals who suffer with lung diseases. Very little work has been conducted on conditions such as interstitial lung disease, pulmonary fibrosis, and others; clearly more research is needed in those unique populations.

Other Pulmonary and At-risk Populations

MI can be applied to other health behaviors relevant to pulmonary disease such as treatment adherence. For example, MI-based interventions have been effective in increasing compliance with continuous positive airway pressure (CPAP) treatment in people with obstructive sleep apnea [3, 74]. A particularly challenging condition with respect to treatment adherence is cystic fibrosis (CF). Increasing the lifespan of individuals with CF requires an intensive regimen of medications and airway clearance therapies, but treatment adherence is a particular challenge in children and young adults coping with the disease [22]. To that end, clinicians in the United Kingdom developed and evaluated a training program in MI for healthcare professionals who work with CF patients [23]. The training was positively received by the healthcare professionals who reported that they subsequently felt relatively confident in delivering MI, but barriers were also identified such as lack of sufficient time with the patient and lack of continuity of care such that the same healthcare professional did not always work with the patient. Consistent with other studies, ongoing training and support in implementing MI were recommended, which will be further discussed below. It remains to be seen whether an MI-based approach can improve adherence in this population, but committed and well-trained healthcare professionals are a necessary initial step. Unique issues must be taken into account in the CF population. Adolescence is a time when striving for independence and autonomy is normal and healthy. From the MI standpoint, teens' reluctance to adhere to CF treatment is not necessarily framed as "resistance" or "noncompliance"; rather the healthcare professional can highlight adolescents' desired sense of self-efficacy as a strength prior to exploring ways in which patients could retain some autonomy while participating in treatment. For younger patients with CF, family involvement is critical, which may include exploring barriers to treatment adherence with parents, highlighting their intentions to do the best for their children and other personal values held by the parents.

Successful implementation of MI has the potential for far-reaching public health impact, e.g., in communities or populations that are at elevated risk for pulmonary conditions. Rates of asthma are disproportionally high in young African Americans as are poorer outcomes [1]. In one study, home-based MI following an emergency room visit for asthma exacerbation in a small group of African-American adolescents resulted in greater motivation to adhere to treatment, but no substantial increases in actual medication adherence [83]. An innovative approach is exemplified by the Detroit Young Adult Asthma project [52]. This project has developed a multicomponent, technology-based intervention to promote use of asthma inhalers which consists of several computer-based sessions facilitated by an avatar, or a digital character that interacts with the participant, that the participant selects. The avatar incorporates MI principles of empathy, optimism, respect for the patient's autonomy, and highlighting of the patient's strengths. These sessions are supplemented with text messages and text-based assessments of mood and behavior (ecological momentary assessment) to reinforce the principles learned in the sessions and obtain readiness to change ratings. Such an innovative and technologically driven intervention, since it relies less on healthcare professional time and effort, has the potential for wide dissemination and may truly represent the future face of MI.

The children of parents who smoke are another at-risk population for pulmonary disease. Passive smoke exposure is associated with higher rates of childhood asthma [91], prompting researchers to develop interventions targeted at parents to prevent or reduce exposure. MI-based interventions in this population have been moderately effective [24, 26, 43], although at least one study observed that reductions in smoke exposure were not sustained over a longer period of time [43]. A cost analysis of an MI plus education intervention versus education alone indicated that the relative expenses of the MI-based treatment were high in the short-term, but there were reduced emergency department visits over the course of 1 year in the group that received the MI intervention [44]. Such findings should be brought to the attention of policymakers and healthcare administrators. Again, second-hand smoke exposure is disproportionally high in low-income and ethnic minority populations; thus any intervention targeted at these groups, including MI, must take into account socioeconomic and cultural factors. One example described by Eakin and colleagues [24] is that, for families who live in urban areas, children need to be near their smoking parents much of the time for safety reasons. Unless such real-world factors are addressed, or at least identified by the healthcare professional as important to the parent, any intervention's chance of success is limited. The healthcare professional can use MI techniques such as reflective listening to explore the relevance of these issues and, when appropriate, highlight the parents' motivation to protect their children.

Fidelity to MI by Pulmonary Healthcare Professionals

Healthcare professional-related barriers to implementing MI in these populations have been identified. Healthcare professionals working with smokers with COPD received several days of training on MI techniques and were subsequently videotaped during a consultation with their patients [25]. Use of a rating scale that measures fidelity to MI techniques revealed that healthcare professionals rarely used the reflections and open-ended questions that are core to MI. The study by Burtin and colleagues on the use of MI to promote physical activity also posited that insufficient training of healthcare professionals in MI skills may have influenced the results [15]. Importantly, these findings are not unique to healthcare professionals caring for pulmonary patients; broader studies of MI fidelity have shown that it is these same techniques that are challenging to adhere to for many beginning MI clinicians, particularly those without previous psychotherapy training [82]. The authors concluded that a few educational sessions of MI are insufficient to teach the complexities of this approach and that ongoing coaching is critical. Another informative study included a one-day MI workshop for RTs, who were then interviewed to assess their perspectives on the feasibility and utility of using MI with their patients [86]. Again, the need for more extensive training and ongoing supervision was highlighted. In addition, RTs felt that MI was very different from their typical communication style with patients and believed that it would require more time than they typically are able to allocate. The implementation of MI in clinical settings is fraught with challenges that are not specific to pulmonary healthcare professionals, and a recent scoping review identified useful recommendations at the level of the healthcare professional, the clinical team, as well as institutional policy to enhance successful integration of MI [47]. These recommendations included training on MI but also ongoing supervision and coaching, encouraging leaders to facilitate the use of MI including ensuring adequate funding, monitoring healthcare professionals' performance, and incorporating MI principles into the institution's shared values and vision. These are ambitious goals that place the responsibility for effective use of MI on the shoulders of not only the healthcare professional, but also the institution.

Implementing MI in a Group Setting

MI-based interventions in pulmonary disease, as reviewed above, are typically delivered individually. MI has been adapted for group settings, primarily for treatment of substance use disorders, but has also been suggested for health behaviors such as weight loss [76]. Velasquez and colleagues [93] present a useful description of adapting MI to a group setting. Suggested strategies include highlighting personal choice (e.g., behavior change is up to the patient), selectively emphasizing and reinforcing change talk, completing a decisional balance exercise where the entire group generates reasons for and against behavior change, and asking for group members' points of view on common themes. The latter is especially important so that the session does not devolve into a series of interventions by the healthcare professional that are exclusively targeted to individual members of the group.

How might an MI-based group be helpful for people with pulmonary disease? This approach may be most applicable for patients participating in PR which is typically a group-based program. In fact, some of the studies reviewed above that attempted MI in the context of PR utilized telephone or home visits, perhaps because the traditional PR setting did not appear conducive to implementing MI. We would argue that MI can be integrated into PR, in a group format, even in a single group session. One of the authors (AM) has used MI principles in group sessions to promote exercise in PR participants. What follows is a detailed description of this intervention, with the caveats that it is a single example of MI deployed in PR and that evidence of its effectiveness is limited to patient satisfaction and not objective measures of engagement in physical exercise. We have included it here so that healthcare professionals contemplating integration of MI in PR programs have an example of its use.

This one-hour group session is the last in a series of four groups with the program psychologist. Thus, group members have already established cohesion among one another and rapport with the facilitator. During this final meeting, patients are coming to the end of the program and are faced with the decision of whether, and how, to continue a regular exercise regimen. The facilitator begins by soliciting aspects of the PR program that group members have found most helpful. Without fail, one or more group members mention the physical exercise component. The facilitator then introduces the reality that, although members agree that the physical exercise is beneficial, continuing it on their own after the program can be challenging. A discussion typically ensues about how behavior change requires more than simply knowing that a behavior is beneficial or harmful. Many group members can relate to this concept with the analogy of smoking and the likelihood that mere knowledge about the adverse effects of smoking is usually not sufficient to prompt them to quit smoking permanently and with ease.

The facilitator then introduces the group decisional balance exercise as recommended by Velasquez [93]. Group members are asked to list the pros and cons of continuing a physical exercise routine, as well as the pros and cons of electing not to exercise, all of which the facilitator lists on a display board. This portion of the session is typically quite lively; for many patients it may be the first time that a healthcare professional has invited them to describe the negative aspects of a healthy behavior such as exercise. The facilitator takes great care to allocate equal attention to the adverse effects of exercise as well as the benefits, in line with the MI principles of highlighting ambivalence and avoiding the urge to persuade. Fig. 6.1 illustrates a typical result of the decisional balance exercise.

Next, the facilitator describes readiness rulers, often with a personal example of rating her own motivation and confidence in making a behavior change. Besides illustrating the concept of the rulers, the example serves the important purpose of humanizing and normalizing ambivalence, as the facilitator intentionally chooses an example of a behavior with a low rating on the readiness ruler. Group members are encouraged to share their own ratings of motivation and confidence. True to MI, the facilitator inquires both about what makes the rating as high as it is ("What makes your motivation to exercise a 3 and not a zero?") and what might make it higher

Pros of Physical Exercise	Cons of Physical Exercise
Will help with better breathing	Makes me short of breath
Muscle strength	Tiring
Will increase my energy	Pain/muscle soreness
Improves my mood	Time-consuming
Helps me feel confident	I might overdo it
Weight loss/management	Difficult to get motivated
Good for heart/lungs/whole body	It’s not part of my routine
Could be a social activity	Gym memberships are expensive
Might increase my lifespan	Going to the gym is a hassle
Will be easier to be active	Embarrassing to exercise in public
Makes my thinking more clear	

Pros of Not Exercising	Cons of Not Exercising
More time to do what I want	Health will get worse
More physically comfortable	Will be more short of breath later
Acceptance of my situation	Quality of life will decrease
Don’t have to worry about overdoing	Maybe shorter lifespan
Save money	More depression and anxiety
	Doctors/family will nag me
	Muscles will get weaker
	Unwanted weight gain
	Will feel guilty

Fig. 6.1 Example of a completed decisional balance exercise in a group Pulmonary Rehabilitation session

(“Now what would it take to get it up to a 5?”). This discussion is usually a time when common themes arise of potential barriers to continuing physical exercise as well as need and ability statements, e.g., “I need to exercise if I want to see my grandkids grow up”; “I’m not sure if I’ll be able to get to the gym.” The facilitator encourages group members to share their point of view about these themes, and members exchange suggestions about how to overcome obstacles to exercising. Throughout the session, the facilitator emphasizes personal choice: “It’s your body and your decision.” The session ends with a discussion of behavioral strategies to increase the likelihood of engagement in exercise (setting realistic goals, rewarding oneself, making exercise part of a structured routine), but MI principles continue to be implemented, e.g., change talk on the part of the patients is highlighted, as is their autonomy.

As stated above, we lack objective follow-up data to assess whether this group MI intervention has been effective in increasing actual engagement in physical exercise following the end of PR. During the first year of the implementation of the MI session, however, patients were administered a written survey as to the helpfulness of the discussion about physical exercise, as well as other topics covered in the group sessions with the psychologist. Of the 98 patients who completed that item of the survey, 77.6% of patients rated the physical exercise discussion as "very helpful." In fact, the physical exercise intervention had the most reliably high ratings of all of the topics patients were asked to rate. Thus, the group MI intervention was generally well received and considered beneficial in this robust sample of PR patients.

Integrating MI: A Case Vignette

The following dialogue details a hypothetical patient–healthcare professional interaction using MI to target physical exercise. Although the details are fictional, this scenario introduces common reactions and concerns patients with pulmonary disease express about exercise. It is important to note that an interaction does not have to be lengthy or formalized; rather, MI techniques can be integrated into a spontaneous conversation with a patient struggling with a difficult behavior.

John is a 70-year-old man with COPD. He is in a PR program and has attended every session. His RT notes today that, although John started to walk on the treadmill as instructed during the exercise session, he stopped after 5 minutes. The RT is speaking with him to use MI to target his physical exercise behavior. The RT also wishes to speak with him about continuing an exercise routine after the program has concluded. Table 6.5 outlines this hypothetical interaction. Suggested responses are in italics with the relevant MI technique in parentheses. Potential roadblocks, cautions, and other notes are included.

Summary

The goal of this chapter was to inform healthcare professionals about the principles of MI and how to apply them to improve outcomes and increase HRQoL for those who have been diagnosed with a pulmonary condition. As we have stressed, training and continuing proctorship in MI is necessary for responsible practice. However, we would also remind readers of the research that factors such as empathy and openness on the part of the clinician are as important, and perhaps even more so, than prescriptive MI techniques as detailed in an MI manual. Thus, we suggest that all healthcare

Table 6.5 Hypothetical case vignette of MI techniques to promote physical activity

Patient Statements	MI Technique and Healthcare Professional's Response	Cautions/Notes
RT: John, I've been noticing that you stopped the treadmill today after a few minutes of exercise. Can you tell me what's going on? John: Yeah, I just don't feel like exercising today.	*(Reflection) Sounds like you're not up to exercising today like you usually do, do I have that right?* *(Affirmation) I want to acknowledge that you attended the program today even though you didn't feel like exercising, good job!* *(Open-Ended Question) What do you think is going on for you today that's making it difficult to exercise?*	Do not begin this dialogue with John by reminding him about the importance of physical exercise or lecturing him.
John: You and my doctors keep telling us to exercise but you don't understand how hard it is.	*(Reflection) Sounds like it's annoying to be lectured all the time about exercising.* *(Emphasize humanity) I hear you, I don't think I'd like always being told what to do.* *(Emphasize control) In the end, only you get to decide how much or how little you exercise. It's your body and your call!*	It may be tempting to defend the healthcare professionals' genuine efforts to help the patient. Avoid statements such as "We only want what's best for you."
John: I don't know, I'm just not sure all of this exercise is worth it. I understand it's supposed to be good for me but it's hard!	*(Double-Sided Reflection) So on one hand you seem to know that the exercise has health benefits, and on the other hand you're finding it difficult to do, is that right?* *(Responding to ambivalence) Tell me what you know about why the physical exercise is good for you. Now tell me what makes it hard to do.* *(Readiness Ruler) On a scale of 0 to 10, how motivated do you feel to do some more exercise today? Why is that number not a zero? What would it take for you to get from (John's number) to (slightly higher number) today?*	The urge to teach, or use logic to persuade, may arise here, e.g., only emphasizing the positive aspects of exercise. But the RT is witnessing ambivalence. It is best to resist this urge and to respond to both sides of John's thought.

(continued)

Table 6.5 (continued)

Patient Statements	MI Technique and Healthcare Professional's Response	Cautions/Notes
John: I know you want me to exercise after this program is over but I really don't know if I can.	*(Reflection) Sounds like you're having doubts about your ability to exercise after the program, is that right?* *(Highlight Ambivalence) What do you think the longer-term benefits of keeping up an exercise routine might be? And what is going to get in the way for you?*	The RT may feel tempted to get ahead of John's own readiness. It is too soon to suggest a gym membership, or buying weights, etc. John is in pre-contemplation or contemplation and the RT should avoid jumping ahead to action.
John: I just don't see me exercising after this program is over.	*(Amplified reflection) What I think I hear you saying is that it's going to be impossible for you to exercise when this program is over.* *(Open-Ended question) What, if anything, would have to change for exercise to be possible?*	Be cautious about protesting to John's statement. Instead, an amplified reflection might prompt John to object to your use of the word "impossible," thereby re-establishing change talk.
John: I think I'm just going to be too lazy to exercise.	*(Positive statements/highlight successes) I don't know if I'd call you lazy. You've been coming here weekly for 6 weeks and exercising most of those days. What do you think is going to get in the way?*	Many individuals who struggle with physical exercise use the term "lazy" to describe themselves. This is a good opportunity to highlight behaviors that will increase their sense of self-efficacy and self-esteem.
John: OK, I know I'm supposed to exercise. But how do I get motivated to get off the couch?	*(Reflection/humanizing) So you might be struggling with how to keep going with exercise. You're not alone, most people find it really difficult to stick with exercise.* *(Eliciting ability statements) You've no doubt done difficult things in the past. Maybe even things that you didn't want to do. How have you done it?* *(Eliciting need statements) Let's review the health benefits if you do continue an exercise routine.*	John's statement here is consistent with the stages of contemplation and preparation. Now the healthcare professional can be more active in introducing behavioral strategies. At the end of this conversation, the RT should offer a summarizing statement of the discussion.

professionals have the potential to integrate MI principles into the care of their patients, with the following basic strategies: (1) Ask open-ended questions that cannot be simply answered in the affirmative or negative; (2) When in doubt, attempt a simple reflection which is a restatement of what the patient said; (3) Listen more than you talk; and (4) Always remember the patient's humanity. His or her behavior may be frustrating but you will always be able to identify one strength and highlight it.

Although MI may seem novel and even antithetical to traditional ways healthcare professionals have been taught to communicate with patients, medical education programs increasingly recognize the potential of MI in promoting health-related behavior change. Thus, the next generation of healthcare professionals is entering practice with this empathic, nonjudgmental communication approach as part of their armamentarium. There is every reason to believe that people with pulmonary disease will benefit.

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Chapter 7
Anxiety, Depression, and Using Evidence-Based Techniques and Strategies to Support Engagement and Adherence

Megan McMurray, Michelle Sisson, and Samantha Schiavon

Introduction

Psychological symptoms are common in patients with chronic respiratory disease, as the prevalence of anxiety and depression is higher in these patients than in the general population [83]. The heightened experience of dyspnea is thought to be a contributing factor to anxiety in these patients, while feelings of depression may be precipitated by restriction in daily activities and subsequent disability caused by the disease. Anxiety and depression symptoms are often comorbid. Importantly, the presence of anxiety and/or depression alongside pulmonary disease is associated with poorer outcomes for these patients, including decreased HRQoL and functional status, increased mortality, longer hospital stays, and higher exacerbation rates [47]. Many of these unfavorable outcomes are related to lower treatment adherence and engagement seen in anxious and depressed patients with chronic medical conditions [26]. Furthermore, the impact of psychological symptoms is not limited to an individual's pulmonary disease, as depression and anxiety can negatively affect a person's interpersonal relationships, inadvertently reducing social support.

Despite the negative influence of anxiety and depression on outcomes for this population, the psychological consequences of pulmonary disease are often insufficiently addressed, at least in the pulmonary medicine community [68]. One reason for this may be that there is significant overlap between the somatic symptoms of

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anxiety and depression and the symptoms of respiratory disease (e.g., dyspnea, fatigue), often leading healthcare professionals to attribute a patient's symptoms only to the physiological mechanisms of the disease. Even if mental health concerns are suspected, respiratory healthcare professionals often report feeling poorly equipped to handle mental health concerns when they present. The purpose of this chapter is to raise awareness among healthcare professionals regarding the secondary psychological difficulties associated with respiratory disease and how these issues can impact patient engagement, adherence, and health behavior change. We aim to provide practical recommendations on how to address these issues within the scope of one's practice. The benefits of having a mental health professional on one's team or at least a partnership with one will also be discussed.

Anxiety and Pulmonary Disease

Anxiety in Patients with Pulmonary Disease

Anxiety symptoms occur at a higher rate among patients with pulmonary diseases compared to the general population [16, 64, 69, 90, 106, 107]. Evidence suggests that among patients with chronic obstructive pulmonary disease (COPD), a disease characterized by permanent pulmonary obstruction and airway inflammation, 13%–50% of patients report moderate-to-severe levels of anxiety [30, 56, 69, 103], with some estimates as high as 74% [106]. These prevalence rates are paralleled among patients with other pulmonary diseases, such as pulmonary hypertension and lung cancer [17, 42, 62, 64].

Similarly, there are high prevalence rates of patients with pulmonary diseases meeting full criteria for psychiatric anxiety disorders. Recent estimates have indicated that 10%–24% of pulmonary patients have a comorbid anxiety disorder, with panic disorder and generalized anxiety disorder (GAD) being the most prominent [16, 69]. Specifically, panic disorder and GAD are estimated to occur in pulmonary patients at a rate that is three times higher than the general US population [64, 69].

Panic disorder is characterized by the presence of recurrent and unexpected panic attacks which typically peak within several minutes and are associated with intense fear or discomfort (see Table 7.1 for detailed symptoms; [3]). Due to these intense fears and accompanying physiological sensations, a panic attack is often mistaken by patients as a heart attack [18]. Approximately 30–75% of patients who present to the emergency room with chest pain complaints are believed to have experienced a panic attack rather than a true cardiac event [10, 21, 33, 52]. Individuals with panic disorder experience recurrent panic attacks and often demonstrate a higher rate of medical services utilization and rehospitalization [21, 108].

Panic attacks are especially prominent in patients with pulmonary disease, as many symptoms associated with these medical conditions (i.e., dyspnea, hyperventilation, chest tightness, and diaphoresis) increase the risk of eliciting a panic attack [16, 64, 69]. Pulmonary patients with comorbid panic disorder experience recurrent panic attacks and subsequently may begin to demonstrate changes in their behavior in an attempt to avoid a future panic attack [3]. This can lead to avoidance of

Table 7.1 Diagnostic criteria for panic disorder and generalized anxiety disorder (GAD)

Panic disorder	Generalized anxiety disorder (GAD)
Recurrent panic attacks reach a peak within minutes and include *at least four* of the following: Palpitation/accelerated heart rate Sweating Shaking Shortness of breath Feelings of choking Chest pain/discomfort Nausea/abdominal distress Feeling dizzy, light-headed, or faint Chills/heat sensations Paresthesia Derealization or depersonalization Fear of losing control Fear of dying	Excess anxiety or worry has been present more days than not *at least the past six months* and associated with *at least three* of the following: Restlessness or feeling on edge Easily fatigued Difficulty concentrating Irritability Muscle tension Sleep disturbance
At least one panic attack has been followed by *at least 1 month* of one or both of the following: Persistent worry about additional panic attacks or consequences of the attacks (i.e., worsening medical condition) Maladaptive behavior related to the attacks (e.g., avoidance of exercise to avoid having panic attacks)	The patient must also exhibit the following conditions: Excessive worry about a number of events (e.g., work, relationships, heath) Difficulty controlling the worry Worry causes significant distress in important areas of functioning (i.e., occupation and social)
Symptoms not attributable to effects of a substance, medication, other medical condition, or better explained by another mental disorder.	Symptoms not attributable to effects of a substance, medication, other medical condition, or better explained by another mental disorder.

behaviors that are necessary to improve their overall health, such as engagement in physical activities, interpersonal interactions, or exercise training [25, 69, 87].

Similarly, GAD is characterized by a 6-month period or longer of excessive anxiety that is extremely difficult to control and encompasses numerous aspects of daily functioning (see Table 7.1 for detailed symptoms; [3]). In order for GAD to be diagnosed, the anxiety must be above and beyond worry that would be expected in the context of sociocultural influences. Additionally, in order to meet full criteria for GAD, the individual must feel unable to control their worry, thereby causing significant distress and impairment in their daily functioning [3]. Ultimately, pulmonary patients with typical anxious reactions to their medical condition (e.g., a recent lung cancer diagnosis) who have demonstrated a reasonable ability to cope with these concerns without exhibiting significant dysfunction would not be concerning for a diagnosis of GAD.

Additionally, when encountering patients in acute care settings, the presence of an adjustment disorder may be especially prominent, as these patients are learning to adjust to changes in their physical functioning. An adjustment disorder is characterized by an emotional or behavioral disturbance that occurs within 3 months following the onset of a clearly identifiable stressor (e.g., onset of a pulmonary condition) [3]. These emotional or behavioral changes must be considered markedly out of proportion to the severity of the stressor and/or cause significant impairment in aspects of daily functioning (i.e., social or occupational environment) [3]. Adjustment disorders can further be specified as presenting with anxiety symptoms or with a combination of anxiety and depressive symptoms. The ability to correctly identify an adjustment disorder will help the patients connect with appropriate psychological interventions to improve coping skills and reduce distress. Without proper treatment, the anxiety symptoms resulting from the patient's inability to effectively adjust to their new physical functioning may lead to limited engagement in physical activity, improper use of oxygen or NIV masks/nasal pillows, and ineffective medication adherence [23, 94].

Psychometrically Sound Screening Measures for Anxiety

Despite the high rate of problematic anxiety among patients with pulmonary disease, in the past, it has been rarely assessed or addressed across various medical settings [65]. Therefore, numerous screening measures have been developed and empirically validated to help professionals quickly identify anxiety symptoms among patients. A selection of the most commonly used and psychometrically sound brief screening measures has been presented in Table 7.2. Each of these screening measures is completed by patient self-report and provides outcomes related to severity of anxiety or specific anxiety disorders.

Generalized Anxiety Disorder-7 Item (GAD-7)

The GAD-7 was developed as a clinical screening tool for the diagnosis and severity of GAD symptoms within a clinical practice [92]. Since its development, the GAD-7 has been validated in medical care settings, including primary care and inpatient psychiatric care [55, 58, 95]. The first two items ("feeling nervous, anxious, or on edge" and "not being able to stop or control the worry") of the GAD-7 assess core anxiety symptoms [92]. The remaining five items relate to cognitive, affective, and behavioral correlates of anxiety.

The GAD-7 demonstrates robust psychometric properties in its ability to detect anxiety symptoms and various anxiety disorders (i.e., GAD, panic disorder, social anxiety, and posttraumatic stress disorder) in primary care settings among adult and elderly populations [58, 95]. Studies have also demonstrated that administering only the first two items on this measure (commonly referred to as the GAD-2) provides similar detectability standards as the full GAD-7 [58]. Therefore, depending on the time restrictions within specific medical care settings, the GAD-2 may be beneficial as a brief screener for anxiety disorders, with the GAD-7 implemented as a follow-up measure to assess the severity of anxiety symptoms as indicated [58]. Overall, it is recommended that the GAD-7 be used within a primary care or inpatient hospital setting when time is limited and healthcare professionals would like to obtain a quick assessment if possible anxiety issues are present and if referral to professional services is required.

Table 7.2 Description of screening measures for anxiety

Screening tool	Items	Completion time	Measures	Rating scale	Pros/cons
Generalized Anxiety Disorder-7 (GAD-7) item	7	1–3 min	Anxiety	(0–4) Normal (5–9) Mild (10–14) Moderate (15–21) Severe	Pro: Very quick, self-report administration. Good for primary care and inpatient settings. Open access available. Cons: Only provides a brief assessment of anxiety and does not capture symptoms specific to other disorders (i.e., panic disorder, posttraumatic stress disorder)
Hospital Anxiety and Depression Scale (HADS)	14	2–5 min	Anxiety Depression	(0–7) Normal (8–10) Borderline abnormal (11–21) Abnormal	Pro: Combined depression and anxiety measure. Strong use among pulmonary patients. Con: Item 4 may inaccurately conceptualize decreased physical functioning from the pulmonary disease as a depressive symptom.
Beck Anxiety Inventory (BAI)	21	5–10 min	Anxiety with a focus on somatic symptoms	(0–9) No anxiety (10–18) Mild-to-moderate anxiety (19–29) Moderate-to-severe anxiety (30–63) Severe anxiety	Pro: Widely recognized across healthcare settings. A brief version specific for primary care is also available (BAI-PC). Con: Items primarily focus on the physical symptoms rather than the cognitive symptoms of anxiety.
Psychosocial Risk Factor Survey (PRFS)	70	10–15 min	Depression Anxiety Anger/Hostility Social Isolation Guardedness	(30–54) Normal (55–59) Mild (60–65) Moderate (66–80) Severe	Pro: Provides detailed descriptions of the patient’s overall presenting problems. Specifically developed for pulmonary patients. Con: Requires longer administration duration.

Hospital Anxiety and Depression Scale (HADS)

The HADS comprises two subscales for measuring anxiety (HADS-A) and depression (HADS-D) [109]. This measure has been validated in somatic, psychiatric, and primary care patients, as well as the general population [12]. Overall, the HADS had demonstrated good reliability in determining the presence of anxiety and depression among adult and elderly patients [12, 27, 43]. However, it should be noted that item 8 of the HADS ("I feel as if I have slowed down") is not considered an accurate representation of depressive symptomology when administered among patients aged 65–80 [27, 43].

Among pulmonary patients, the HADS has been well validated among patients with mild-to-severe COPD [81, 89]. When examining the specific subscales, the HADS-D was shown to have improved detection sensitivity with the removal of item 4 ("I feel as if I am slowed down"), whereas the HADS-A subscale was shown to have good sensitivity without any modifications [81]. Overall, it is recommended that the HADS measure be administered to patients with pulmonary disease when there is a concern of both depression and anxiety problems.

Beck Anxiety Inventory (BAI)

Perhaps the most universally recognized and utilized measure of anxiety, the BAI [6] measures the severity of anxiety symptoms with a particular focus on the somatic presentation of anxiety (e.g., feeling of choking, dizziness, and increased heart rate), which has been shown to negatively impact adherence and engagement with pulmonary therapies, such as the use of inhalers, oxygen therapy, smoking cessation, and physical activity [23, 34, 93, 94]. The BAI is well validated among pulmonary patients and demonstrates robust sensitivity for detection of anxiety symptoms among this population [81]. As medical care settings often necessitate time-efficient measures for patients, a shorter BAI was developed specifically for use in primary care settings. This BAI-PC is composed of seven items derived from the measure's original 21 items and uses a clinical cutoff score of 5 to determine the presence of an anxiety disorder [7]. The BAI-PC has been shown to be highly effective in screening for panic disorder and GAD among primary care patients [7] and serves as an alternative for professionals in various medical settings. Given the strong negative effects of somatic anxiety symptoms on pulmonary therapy, it is recommended that this measure be administered when a patient's limited engagement in pulmonary treatment (e.g., exercise and oxygen therapy) may be better explained by the presence of an anxiety disorder.

Psychosocial Risk Factor Survey (PRFS)

Although the PRFS is the longest of the selected screening measures, it also provides a more comprehensive assessment of psychological factors in patients with pulmonary disease, including depression, anxiety, anger/hostility, social isolation, and emotional guardedness [28]. The PRFS was specifically developed to assess these important psychological distress components among pulmonary and cardiac patients [28]. This scale is validated for patients in cardiac rehabilitation programs and would likely be as useful in pulmonary rehabilitation patients. It is recommended that this measure be administered to patients engaged in pulmonary or cardiac rehabilitation programs, as it was specifically designed for this population and requires additional time to complete that may not be available within an inpatient setting.

Impact on Engagement, Adherence, and Outcomes

Anxiety can negatively impact a breadth of outcomes among pulmonary patients, including avoidance of specific behaviors, decreased adherence to treatment regimen, increased risk for rehospitalization, and poor HRQoL [19, 48, 56, 87, 106]. Given the prevalence of anxiety among patients with pulmonary disease, it is necessary to understand the multifaceted impact of anxiety across various health-related outcomes.

Dyspnea–Fear Cycle

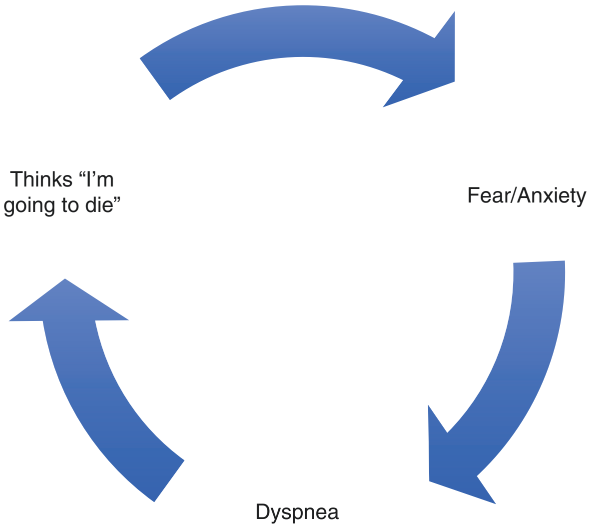
There is strong evidence establishing a connection between the respiratory symptom of dyspnea and anxiety or dyspnea-related fear [5, 25, 48, 69, 72]. Psychological theories posit that anxiety often occurs when a patient experiences dyspnea and misinterprets it as a life-threatening event. This misinterpretation may lead to a heightened panic response, and subsequently exacerbates physiological arousal (i.e., increased heart rate, hyperventilation, and sweating), which leads to strengthened or additional dysfunctional cognitive reinterpretations of the physical symptoms [5, 16, 48].

In this model, the patient continually cycles between experiencing dyspnea, fear/anxiety and worsening dyspnea, and physiological symptoms (see Fig. 7.1). Over time, this dyspnea–fear cycle can lead to recurrent panic attacks [64], overall increased anxiety [16, 69], and decreased HRQoL [48]. Often in an attempt to avoid recurrent panic attacks and reduce anxiety, patients may begin to avoid any activity that induces dyspnea [87]. This is particularly harmful among pulmonary patients, as this cycle can lead to decreased exercise training and engagement in activities of daily living [25, 75, 87]. Ultimately, this inactivity due to dyspnea-related fear may produce negative effects on lung-functioning capabilities and overall HRQoL [25, 48], leading to deconditioning. However, it has been shown that adherence to exercise training can reduce anxiety and avoidance behaviors [19, 48] as well as other health-related outcomes, including hospitalization, respiratory mortality, and acute exacerbations [70, 71, 98] (see Chap. 8).

Healthcare Utilization

In addition to the association between anxiety and dyspnea, there is also a strong connection between anxiety and rehospitalizations that is likely related to the fear–dyspnea cycle [40, 56]. Patients with pulmonary disease and anxiety utilize healthcare services, including general practitioner and emergency treatment services, at a

Fig. 7.1 Dyspnea–fear cycle



higher rate compared to patients with pulmonary disease without anxiety [56]. Additionally, patients with obstructive pulmonary diseases are at higher risk for rehospitalization, which may occur as soon as 1 month after discharge [24, 40]. Therefore, identifying anxiety symptoms and directly implementing appropriate psychological intervention, such as cognitive–behavioral therapy (CBT), may reduce rehospitalization rates and overall healthcare utilization.

Functional Impairment

Anxiety symptoms can further impede rehabilitation treatment, resulting in impaired functional capabilities [56, 106], increased risk of mortality [69], and reduced HRQoL beyond that expected by the disease alone [1, 42, 48]. Several studies have shown that anxiety has a greater negative impact on the patient's functional status than expected with the disease alone, even surpassing lung-functioning capabilities [35, 104] and disease severity [56]. When patients inaccurately view themselves as severely impaired, they are less likely to fully engage in physical activity, social functioning, or daily living activities [56, 77]. Additionally, this skewed negative perception increases hospital admissions and acute exacerbations [40, 60].

Depression and Pulmonary Disease

Depression in Patients with Pulmonary Disease

Similar to anxiety, depressive symptoms can also present in individuals with pulmonary conditions and can impact the course and treatment of their disease. The most common form of depression is major depressive disorder (MDD), which is

Table 7.3 Diagnostic criteria for major depressive disorder (MDD) and adjustment disorder

Major depressive disorder (MDD)	Adjustment disorder
Five or more of the following symptoms have been present during a 2-week period and *at least one* of the symptoms is either (1) depressed mood or (2) loss of interest or pleasure: Depressed mood most of the day, nearly every day Diminished interest or pleasure in almost all activities most of the day, nearly every day Decrease or increase in appetite nearly every day or significant weight change (more than 5% of body weight in a month) Insomnia or hypersomnia nearly every day Psychomotor retardation or agitation Fatigue or loss of energy nearly every day Feelings of worthlessness or excessive guilt Difficulty concentrating or indecisiveness Recurrent thoughts of death, suicidal ideation, specific plan for completing suicide, or a suicide attempt	Development of emotional or behavioral symptoms in response to an identifiable stressor *within 3 months* of the onset of said stressor Symptoms or behaviors are clinically significant and include *one or both* of the following: Marked distress that is considered out of proportion to the severity of the stressor Significant impairment in multiple areas of functioning (e.g., social, occupational)
Symptoms cause clinically significant distress or impairment in multiple areas of functioning (e.g., social, occupational)	Symptoms do not meet criteria for another mental disorder nor are considered an exacerbation of a preexisting mental disorder
Symptoms not attributable to effects of a substance, medication, or other medical condition or better explained by another mental disorder	Symptoms do not represent normal bereavement
Patient has never experienced a manic or hypomanic episode	Once the stressor is removed, the symptoms do not persist for more than 6 months

characterized by markedly depressed mood, loss of interest and pleasure in activities, and a variety of related symptoms, such as sleep or appetite disturbances, fatigue, and feelings of worthlessness (see Table 7.3 for detailed symptoms; [3]). Adjustment disorder with features of depression is also a common diagnosis for individuals who have recently discovered that they are suffering from a chronic medical condition. These individuals do not meet full criteria for MDD, but show significant distress in reaction to receiving their medical diagnosis (see Table 7.3 for detailed symptoms; [3]). Depressive symptoms can be assessed quickly with screening assessments. Determining whether a patient is suffering from depression and directing them to an appropriate treatment option is important, as this type of disorder can influence engagement, adherence, and outcomes of pulmonary care.

Prevalence

The reported prevalence of depression in patients with pulmonary disease varies based on the specific respiratory disease. A recent meta-analysis found a mean depression prevalence of 27.1% among COPD patients across 19 research studies, with estimates ranging from 15.2% to 35.7% [67]. Estimates of depression in patients with interstitial lung disease are somewhat similar to COPD and range from 10% to 49% [20]. Heterogeneity across the studies included in each of these reviews was high, which may have contributed to the variability of prevalence estimates [20, 67]. This underscores the need for future standardized research studies in order to establish increasingly accurate estimates. Smaller scale studies examining mental health comorbidities in patients with bronchiectasis have found that approximately 20% of these patients experience depression [73, 76]. The presence of depression symptoms in patients with pulmonary conditions is often underdetected, which is why understanding of depressive symptomatology in pulmonary settings is imperative in order to improve patient care [59].

Depressive Symptoms

Patients may present with a variety of symptoms that could signify depression. The hallmark symptoms are persistent depressed mood and loss of interest or pleasure in activities previously enjoyed. Depressed mood can be described as sadness, hopelessness, or an absence of experiencing feelings. Anhedonia (lack of pleasure) or losing interest in activities can manifest in various forms. For example, an individual with depression may not engage in previously enjoyed hobbies, withdraw socially, or experience a decrease in sexual desire [3].

In addition to these primary symptoms of depression, patients may experience several other accompanying features of this disorder, such as sleep disturbance, manifested as difficulty falling asleep, waking prematurely, or sleeping excessively. Fatigue, even after expending minimal energy, is also frequently reported. Patients experiencing depression might move, think, and speak slower than normal. The opposite can also occur such that a person with depression may have difficulty sitting still and displays fidgeting behaviors. Appetite changes are also common and can present as eating either less or more than normal. Significant weight loss or gain can accompany these changes in appetite. Some patients mention difficulties with concentrating, memory, or making routine decisions. Depressed patients can have excessively negative evaluations of their self-worth or disproportionate feelings of guilt related to seemingly trivial past events. Lastly, thoughts of death, suicidal ideation, or suicide attempts can be indicative of depression. These may be passive thoughts about death, recurrent thoughts of completing suicide, or thoughts about specific plans for ending one's life [3].

Importantly, depressive-like symptoms can occur in some patients as a reaction to being diagnosed with a pulmonary condition even though they may not meet full diagnostic criteria for major depressive disorder (MDD). If patients show marked distress and reduction in mood after receiving a diagnosis, but do not exhibit the aforementioned symptoms consistent with MDD, they may be experiencing an adjustment disorder with features of depressed mood [3]. While a psychiatric diagnosis needs to be determined by a licensed mental health professional, being aware of depressive symptomatology as a medical professional can help facilitate the identification of patients who could especially benefit from a potential referral for treatment. Ideally, all patients with pulmonary disease should be screened for depressive symptoms given increased risk compared to the general population.

Psychometrically Sound Screening Measures for Depression

Brief screening assessments for depression can be administered to patients with pulmonary conditions. Table 7.4 describes the properties of four depression screeners that have demonstrated good psychometric properties, such as adequate validity and reliability [9, 28, 57, 109]. These screening tools are quick to administer and score and can assist in determining whether a patient might benefit from further psychological evaluation and/or mental health intervention.

Table 7.4 Description of screening measures for depression

Screening tool	Items	Completion time	Measures	Rating scale	Pros/cons
Physician Health Questionnaire (PHQ-9)	9	3–5 min	Depression (presence and severity)	(0–4) None (5–9) Mild (10–14) Moderate (15–19) Moderate/severe (20–27) Severe	Pros: Quick, self-reported administration. Good for primary care and inpatient settings. Open access available. Con: Can result in false positives for depression and should be used for screening rather than diagnosis.
Hospital Anxiety and Depression Scale (HADS)	14	4–5 min	Anxiety (HADS-A) Depression (HADS-D)	(0–7) Normal (8–10) Borderline (11–21) Abnormal	Pro: Combined depression and anxiety measure. Strong use among pulmonary patients. Con: Item 4 may inaccurately conceptualize decreased physical functioning from the pulmonary disease as a depressive symptom.

(continued)

Table 7.4 (continued)

Screening tool	Items	Completion time	Measures	Rating scale	Pros/cons
Beck Depression Inventory (BDI-II)	21	5 min	Depression (presence and severity)	(0–13) Minimal (14–19) Mild (20–28) Moderate (29–63) Severe	Pros: Brief and widely recognized across healthcare settings. Cons: Wordings of certain questions are culturally specific. Some items focus on physical symptoms that may result in false positives for pulmonary patients.
Psychosocial Risk Factor Survey (PRFS)	70	10–15 min	Depression Anxiety Anger/Hostility Social Isolation Guardedness	(30–54) Normal (55–59) Mild (60–65) Moderate (66–80) Severe	Pro: Provides detailed descriptions of the patient's overall presenting problems. Specifically developed for pulmonary patients. Con: Requires longer administration duration.

Patient Health Questionnaire (PHQ-9)

The PHQ-9 is a nine-item self-report scale with scores that indicate depression severity as well as proposed treatment actions, such as creating a treatment plan, referring for psychological counseling, or considering the addition of psychotropic medications. Reliability among primary care patients, including those with pulmonary conditions, demonstrated a Cronbach's alpha of 0.89. Compared to mental health professional depression diagnoses, sensitivity and specificity both equaled 88% [57].

Hospital Anxiety and Depression Scale (HADS)

The HADS is a 14-item self-report scale intended to distinguish between anxiety and depression in medical patients. It is comprised of two subscales measuring anxiety (HADS-A) and depression (HADS-D) [109]. This measure has been validated across various patient populations including patients with mild-to-severe COPD [81, 89]. Administering this assessment would be beneficial for professionals attempting to determine whether a patient's apparent symptomatology more accurately reflects depression or anxiety.

Beck Depression Inventory (BDI-II)

The BDI-II is a 21-item self-report scale with four options under each item ranging from *Not present (0)* to *Severe (3)*. The total score indicates a patient's level of experienced depression (e.g., minimal, mild, moderate, and severe). This measure has been validated across several patient populations and has demonstrated adequate internal consistency ($\alpha = 0.91$), test–retest reliability (Pearson $r = 0.93$), and convergent validity (Pearson $r = 0.71$) [8, 9, 81].

Psychosocial Risk Factor Survey (PRFS)

The PRFS is a 70-item self-report scale that assesses psychosocial risk factors that can impact cardiopulmonary disease, including depression, anxiety, anger/hostility, social isolation, and emotional guardedness. This measure was specifically designed to be administered to pulmonary and cardiac patients and has been validated for patients in cardiac rehabilitation programs [28]. Of the selected measures discussed herein, the PRFS is the longest, but it provides a comprehensive assessment and should be utilized to determine areas of concern.

Suicidal Ideation Endorsement

Each of the assessments listed in Table 7.4 includes items related to suicidal ideation. It is important to review patient responses on the aforementioned screening tools prior to the conclusion of the appointment in order for potential suicidal ideation to be addressed promptly. Endorsement of suicidal ideation, whether via items on a questionnaire, direct patient report, or reports from a patient's support network, requires immediate attention. The American Association of Suicidology (AAS) has compiled a list of the top ten warning signs for suicide (facilitated with the acronym IS PATH WARM), which are ideation, substance use, purposelessness, anxiety, trapped, hopelessness, withdrawal, anger, recklessness, and mood change. Patients who are displaying several of these warning signals may be at risk for suicide [49].

Suicidal statements may be passive or active. For example, a patient making a passive suicidal statement may remark that they would be "better off dead" instead of dealing with the stressors of their pulmonary condition. In this type of instance, the patient is feeling hopeless but has not stated intention to end their life. Of course, it is imperative to evaluate this further. Active suicidal statements indicate that the patient has intent to complete suicide or has even made plans regarding the manner in which they would do so. In the case of an actively suicidal patient, emergent assessment by a qualified mental health professional is necessary. Patients who are making passive suicidal ideation statements (and have denied having a plan, means, or intent) should be referred to a mental health professional or a consult can be arranged. Healthcare professionals are advised to become familiar with their institution's protocol and policies for the assessment and management of suicidal ideation. If your institution does not have a protocol in place, consider consulting with a mental health professional to develop policies and guidelines for assessing and managing suicidal ideation.

Impact on Engagement, Adherence, and Outcomes

Depression can affect a patient's engagement in activities. As previously mentioned, individuals with depression often present with anhedonia, loss of interest in activities, low energy, and feelings of worthlessness. When a patient lacks the desire or sense of ability to engage in enjoyable activities, this can lead to a vicious cycle and further exacerbation of symptoms. For example, not participating in pleasurable activities often results in more disengagement from these pastimes, which causes additional decrease in mood or intensifies feelings of worthlessness. In turn, lower mood and severe feelings of worthlessness have the consequence of even less involvement in activities, subsequently exacerbating depressive symptoms [102]. Pulmonary patients who are also experiencing depression have a compounded situation, since their medical condition often leads to limited energy and mobility in and of itself. Not only does limited energy and ability to engage in activities worsen depressive symptoms, but also in turn, elevated levels of depression can increase pulmonary symptoms. For example, becoming easily fatigued due to depression can increase the likelihood of experiencing dyspnea. Additionally, elevated levels of depression can further increase patients' perception of pain [101]. Individuals with depression may also engage in social activities less frequently, thereby inadvertently reducing their social support system, which is a critical element for coping with a chronic medical condition. Similarly, impaired sexual functioning or decreased sexual desire can lead to relationship strain and reduced HRQoL.

In addition to engaging less with pleasurable and social activities, patients experiencing depression may also adhere less to treatment regimens. Individuals with depression alone are three times less likely to adhere to medication regimens [26]. This is further compounded by the need for patients with pulmonary disease to comply with recommended oxygen use along with adhering to medication use. Compliance with oxygen use in individuals with COPD ranges from 45% to 70%, and this rate is likely even lower in individuals suffering from comorbid depression [53]. Moreover, depressed patients are more prone to discontinuing pulmonary rehabilitation [54].

Treatment outcomes for patients with pulmonary conditions can also be negatively affected by comorbid depression. Depression is associated with extended hospital stay for pulmonary patients [31]. Furthermore, pulmonary patients who experience depression are more likely to continue smoking tobacco. Smoking can speed the deterioration of airways and raise the risk of mortality [13]. Unfortunately, depression is also associated with increased risk of 3-year mortality in patients with severe COPD [31].

Evidence-Based Treatment for Anxiety and Depression

Pharmacological Treatments

Various trials have demonstrated effective pharmacological interventions to reduce anxiety and depressive symptoms among patients with pulmonary diseases. Although benzodiazepine medications are often prescribed for panic attacks as a "rescue" medication for acute panic, benzodiazepines are not recommended to treat mental health concerns for patients with pulmonary disease as these medications can induce respiratory depression and compromise lung function [16, 69] and have potential for abuse and/or dependence [74]. Evidence suggests that other classes of medication, such as buspirone (anxiolytic), nortriptyline (tricyclic antidepressant), and sertraline (selective serotonin reuptake inhibitor, SSRI), are better alternatives for the management of mood and anxiety in patients with pulmonary conditions [16].

Although buspirone is an anxiolytic, it is not chemically related to benzodiazepines and, therefore, does not produce adverse sedation and respiratory depression effects. Overall, evidence regarding the efficacy of buspirone medication among pulmonary patients has been mixed. Some trials have shown buspirone to be effective in reducing anxiety and dyspnea as well as beneficial in improving exercise tolerance among patients with COPD [4, 105]; however, these effects were not replicated in a subsequent trial [88].

It has been suggested that antidepressant medications represent a safer alternative to benzodiazepines in treating patients with pulmonary disease with problematic anxiety symptoms [69]. One theory postulates that the serotonergic system mediates the connection between anxiety and dyspnea symptoms among patients with pulmonary conditions [69, 91]. Therefore, antidepressants may prove beneficial to reduce anxiety, dyspnea, and depressive symptoms among patients with respiratory disease. One study examining nortriptyline found it to be effective in reducing depression and anxiety symptoms among patients with COPD [15]. Another study found sertraline to be well tolerated among patients with COPD [91]; however, this small study included only seven patients with COPD, and further research needs to be conducted to definitively determine the efficacy of sertraline among patients with pulmonary conditions. These effects are unlikely to be limited to sertraline and could be generalizable to most or all SSRIs.

Although various pharmacological interventions have demonstrated effectiveness for treating anxiety and depressive symptoms, patients with pulmonary disease may be resistant to pharmacotherapy. Patients with pulmonary conditions are often prescribed a multitude of medications to treat their medical condition(s), and are on average prescribed 2–9 medications to treat their pulmonary disease [14]. Due to this high volume of medications, it is not surprising that one study found that more than 70% of patients with pulmonary disease refused the addition of antidepressant pharmacotherapy [105]. Each additional medication further complicates the medication regimen of these pulmonary patients, requiring further cognitive capacity to manage the variety of pharmaceuticals being taken, leading to increased risk of cross-medication effects, adverse reactions, and difficulty maintaining accurate medication adherence. Taken together, these observations highlight the importance of offering nonpharmacological treatments to help patients develop skills to manage their anxiety and/or depression symptoms. See Chap. 9 for more information regarding other nonpharmacological treatments.

Psychological Treatments

Cognitive–behavioral therapy (CBT) remains the gold standard treatment approach to reducing anxiety and depression among patients with pulmonary disease. In addition, relaxation interventions have also been shown to be a highly effective treatment approach to reduce anxiety symptoms among pulmonary patients [16, 61]. Relaxation interventions can be administered in combination with CBT or as a stand-alone practice.

Progressive muscle relaxation (PMR) has a longstanding history as an effective relaxation intervention to reduce anxiety in patients with pulmonary disease [29, 61, 100]. PMR involves a sequence of deep muscle relaxation through tension-release movements that progress through muscle groups from head to toe [11]. PMR can be taught to patients in person or through auditory listening modalities and demonstrated effectiveness for anxiety and dyspnea reduction [36, 84]. Although prior studies on PMR have primarily examined the technique as a method to reduce anxiety, it also appears to be an effective intervention to reduce both anxiety and depression symptoms among patients with pulmonary arterial hypertension. After 12 weeks of regular PMR practice, patients with pulmonary arterial hypertension had reduced anxiety and depression symptoms as well as increased HRQoL [61].

Another commonly utilized relaxation technique, diaphragmatic breathing, is a commonly used method to help reduce anxiety and dyspnea among patients with pulmonary disease. Diaphragmatic breathing or deep breathing involves expanding and contracting the diaphragm during breathing so that the stomach (rather than chest) rises and falls with each breath. This type of deep breathing technique helps to reduce autonomic arousal, leading to decreased anxiety. The practice also serves to strengthen the diaphragm, allowing patients with pulmonary disease to use less effort and energy to breathe [38]. Evidence supports the use of diaphragmatic breathing and PMR relaxation techniques in combination with CBT to improve physical functioning as well as reduce anxiety and depression [16, 61]. It should be noted that deep breathing can be quite difficult for patients with obstructive lung diseases such as COPD, and pursed-lip breathing is often taught in lieu of diaphragmatic breathing, as it likely induces a similar relaxation response.

Combined Pharmacological and Psychological Treatments

For patients who are amenable, the combination of pharmacological and psychological treatment may be an effective option. In clinical populations, the combination of pharmacological and psychological interventions has demonstrated effectiveness in reducing symptoms of depression and anxiety [46, 78]. Medication can be useful in reducing mood symptoms to a manageable level to allow the patient to successfully engage in the psychological treatment(s). Conversely, engagement in psychotherapy enables patients to develop skills to manage their anxiety or depression symptoms over long-term outcomes [79]. Therefore, due to the slower onset of benefits resulting from psychotherapy, it has been suggested that combined use of pharmacological and therapeutic interventions will increase a patient's overall engagement in care and development of coping skills [94].

Using Cognitive–Behavioral Techniques and Other Empirically Supported Strategies to Enhance Pulmonary Patient Engagement and Adherence

Cognitive–Behavioral Therapy

Although several evidence-based treatment options for anxiety and depression were discussed in the previous section, the focus for the remaining portion of the chapter will be CBT, as it has demonstrated robust effectiveness in the treatment of these disorders. CBT has strong support for reducing symptoms of anxiety and has even been shown to outperform pharmacological treatments in the long term [44]. CBT has been found to be as effective as pharmacological treatments in reducing symptoms and remission across varying severity levels of depression [99]. Additionally, combining CBT with pharmacological treatment enhances the rate of recovery as compared to treating depression with medication alone [45]. Compared to other active psychological treatments (e.g., relaxation techniques, psychodynamic therapy), CBT is equally effective or superior in reducing symptoms of depression [44].

Most research surrounding the effectiveness of CBT for anxiety and depression involves participants who do not have comorbid medical conditions. However, there is emerging evidence that CBT improves symptoms of anxiety and depression in patients with pulmonary conditions such as COPD [32, 97]. As compared to routine care, COPD patients treated with CBT have shown decreased ratings of dyspnea

[63]. Furthermore, patients with comorbid COPD, anxiety, and depression who were treated with CBT had improvements in exercise capacity and fatigue in addition to a reduction in anxiety and depressive symptomatology [66]. Unfortunately, there are few studies that have examined the effectiveness of CBT in individuals with pulmonary conditions, and most have small sample sizes [82, 94]. Additional randomized controlled trials with larger sample sizes are needed to examine CBT in individuals with pulmonary conditions and comorbid anxiety and depression for confidence in treatment effects.

Cognitive–Behavioral Model

The treatment principles of CBT are based around the core concepts of the cognitive–behavioral model (see Fig. 7.2). Two of the foundational concepts of this model are that our cognitions influence our emotions and behaviors and our behaviors affect our cognitions and emotions. Essentially, our thoughts, emotions, and behaviors are all related. When an event occurs, we cognitively appraise the situation, react emotionally to this appraisal, and act accordingly. Sometimes, especially in individuals suffering from anxiety and depression, cognitions can be distorted and potentially debilitating [102].

Patients with pulmonary disease who are experiencing anxiety and depression may have dysfunctional thoughts related to their inability to do things or hopelessness about their condition. For example, they may feel sure that something bad will happen, that they are a failure, or that they do not have a future. Fortunately, there are cognitive and behavioral techniques that can remediate these dysfunctional thought patterns. Mental health professionals can work with

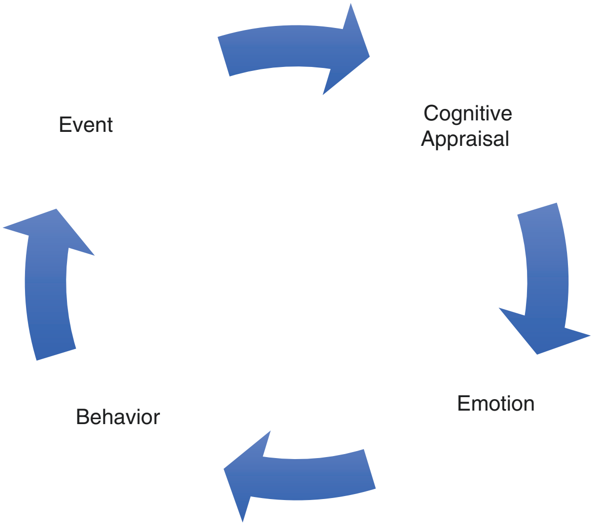


Fig. 7.2 Cognitive–behavioral model

patients to restructure maladaptive cognitive processes. This involves helping the patient identify cognitive distortions and dysfunctional thoughts in order to promote a more rational style of thinking [102]. For example, a patient may question the benefit of incorporating exercise into their daily routine if they have been smoking tobacco cigarettes for several years or have not yet ceased smoking. In this case, the professional can help the patient identify maladaptive all-or-nothing thinking and restructure this thought process to recognize that increasing physical activity is a positive behavior change that will benefit their health, despite their smoking status.

Behavioral techniques can be suggested by mental health or pulmonary rehabilitation professionals to help patients reduce their symptoms of anxiety and depression. For example, patients who are avoiding exercise due to the fear of experiencing dyspnea can be encouraged to engage in activity under supervision and can be gradually exposed to exercise. Relaxation techniques, such as the previously described diaphragmatic breathing or PMR, can also assist patients in reducing their experienced anxiety. For patients who are experiencing depression, behavioral activation (see Chap. 11) can help the patient become more engaged and give them a sense of accomplishment. Working collaboratively with the patient to identify specific activities and developing a realistic plan to employ these activities can lead to an improvement in mood. These activities should be scheduled in the patient's calendar to increase accountability and likelihood that the activity will actually be completed. Furthermore, the activities should be enjoyable and something that will give the patient a sense of mastery and accomplishment [102].

The utilization of formal CBT requires specific and extensive training as well as a clinical background. Therefore, providing this intervention is outside the scope of practice for most pulmonary healthcare professionals, and patients should be referred to a mental health professional for CBT. For mental health professionals (e.g., psychologists, mental health counselors, psychiatrists, and social workers) interested in additional focused training in CBT, in-person and online training and certification is available through The Beck Institute. For mental health professionals working in the Veterans Health Administration system, programs that provide competency-based training in CBT are available.

Recommendations for Healthcare Professionals

The importance of incorporating psychological assessment into treatment for pulmonary disease has already been reviewed, as psychological factors may impact adherence to treatment and subsequent outcomes. When significant psychological concerns are identified, healthcare professionals can refer to a behavioral specialist (e.g., psychologist, psychiatrist, and licensed mental health counselor) for further evaluation and treatment; however, healthcare professionals are well equipped to provide various interventions to improve psychological functioning for patients with pulmonary disease, even in the absence of a mental health professional. Below are examples of practical interventions that healthcare professionals from diverse backgrounds can provide or suggest to patients with lung disease to improve psychological functioning, thereby improving patient adherence and engagement.

Identify a Mental Health Professional Team Member Every clinician working with individuals with pulmonary disease should be screening for the presence of anxiety and depressive symptoms, as this screening can be highly valuable in at least identifying those patients who might require a more detailed mental health evaluation. Healthcare professionals working in family and primary care settings are often comfortable screening for these symptoms and prescribing psychotropic medications and providing therapeutic contact as needed. Pulmonary specialists may focus more on the physiological aspects of the disease, although they often have access to pulmonary rehabilitation programs in which a psychological assessment can be conducted. In the case that the existing pulmonary rehabilitation program does not offer this service, healthcare professionals should seek a partnered relationship with a mental health professional or at least a strong referral resource. Generally, these professionals will possess a master's degree or above and fall into one of the following disciplines: clinical psychologist, counselor, social worker, or addictions counselor.

Refer Patients to Pulmonary Rehabilitation Pulmonary rehabilitation (PR) is considered an essential component of the standard of care for individuals who are symptomatic from their pulmonary conditions [2]. Studies have demonstrated that symptoms of anxiety and depression improve following completion of PR programs [39, 80]. Despite the emerging evidence to support the beneficial effect of PR in improving anxiety and depression symptoms in individuals with pulmonary disease [37], the majority of patients with pulmonary disease never participate in PR [41]. Recent guidelines support the inclusion of psychological interventions as a component of comprehensive PR programs [85].

Let Patients Know That Exercise Is Safe for Them Research supports the benefits of exercise for improving depression and anxiety symptoms [86]. However, many patients with pulmonary disease report fears regarding the potential impact of exercise on their medical condition. Many patients want reassurance from their primary care healthcare professionals (physicians or pulmonologists) that it is safe for them to engage in exercise. When recommending pulmonary rehabilitation, patients' concerns should be acknowledged and normalized, and healthcare professionals can offer reassurance and details about the quantity and intensity of supervised exercise that is safe for them. Exercise is one of the most important but one of the most difficult activities for individuals with respiratory disease to do, despite the beneficial effects of exercise on diseases like COPD. A referral to PR is useful in helping a patient who is unsure of how to get started with physical activity, as exercise is one of the primary interventions to improve psychological functioning that all PR programs are currently providing.

Encourage Hobbies, Interests, and Other Activities Patients with chronic respiratory disease often give up or lose interest in activities they previously enjoyed because they believe the effort to engage in these activities is not worth the benefits.

Healthcare professionals can assist patients with brainstorming ways to adapt or modify previously enjoyed activities (e.g., sitting on a stool while cooking if standing is difficult) to facilitate participation so that patients can continue to enjoy the mood-boosting benefits of engaging in these activities. Healthcare professionals may encourage patients who require oxygen to bring a hands-free oxygen carrier to activities they enjoy so they can participate in activities like golf, gardening, going fishing, or walking the dog. If a patient's hobby involves a lot of dust, like woodworking, they can be encouraged to wear a mask in a well-ventilated area.

Encourage and Facilitate Social Support Individuals with pulmonary disease who lack adequate social support often have worse health outcomes [50]. Healthcare professionals can assist with enhancing the patient's social support by acting as a caring professional and engaging in active listening and motivational interviewing techniques (see Chap. 6), as well as engaging in patient advocacy efforts and facilitation of resource acquisition. Patients should be encouraged to utilize existing social support networks by seeking support from family, friends, and other PR program participants if the patient is involved in PR. Healthcare professionals should encourage patient involvement in support groups that facilitate the sharing of personal experiences, emotions, successful coping skills, and disease-related information. Support groups may be run by patients or facilitated by mental health or healthcare professionals. Social support can also be facilitated through the involvement of a patient's spouse, caregiver, or support person. Should significant interpersonal or family conflicts surface, referral to a mental health professional for assessment and treatment of problematic dynamics is recommended.

Discuss Sexual Health and Functioning Pulmonary disease often negatively impacts sexual intimacy and functioning, but many patients are hesitant to discuss sexual health issues with their doctors. Depression and anxiety can further affect sexual interest and functioning beyond pulmonary disease alone [51]. Healthcare professionals are well positioned to improve psychological functioning and HRQoL in patients by offering a safe place to discuss sexual issues and providing education to those patients willing to engage in conversations about sex.

Provide Resources for Relaxation Exercises Individuals with or without pulmonary disease tend to breathe faster and shallower when stressed and/or experiencing strong emotions, which can lead to shortness of breath and sometimes panic. As feeling short of breath is especially problematic for patients with lung disease, strategies to control the distressing experience of breathlessness have been taught to patients with pulmonary disease for a long time. Patients with pulmonary disease can minimize the risk of becoming breathless during times of stress or high anxiety by using relaxed breathing techniques, which can easily be provided by healthcare professionals. Relaxed breathing (often called diaphragmatic breathing) is a way of interrupting the "Fight or Flight" response and promoting the body's natural relaxation response. Research has demonstrated that interventions such as mindfulness-based therapy, relaxation, and yoga lead to reduced anxiety and depression and improved physical outcomes (i.e., lung function, exercise capacity, fatigue, and dyspnea) in individuals with pulmonary disease and comorbid psychological distress [96]. Various mobile phone applications and websites exist for relaxation exercises, including breathing retraining, progressive muscle relaxation, and mindfulness meditation.

The above interventions are only a sampling of ways that healthcare professionals can promote psychological functioning and improve HRQoL in patients with pulmonary disease. Despite various ways that healthcare professionals can intervene when a patient presents with significant emotional concerns, all healthcare professionals should have a partnered relationship with a behavioral professional and be prepared to offer a referral when indicated. Psychological interventions can be effective in reducing distress and improving HRQoL, thereby improving patient engagement and adherence, and should therefore be a part of every comprehensive treatment plan for individuals with pulmonary disease.

Conclusions

Anxiety and depression are common and significant comorbidities in patients with pulmonary conditions. Psychological issues can impede patient engagement and adherence, leading to poor outcomes, including increased mortality rates, more frequent exacerbations, longer hospital stays, and reduced HRQoL and functional status. Despite the increasing awareness of the prevalence and importance of anxiety and depressive symptoms compared to the general population, mental health problems often go undiagnosed and, therefore, untreated in patients with respiratory disease. Thus, screening for anxiety and depression is crucial in this population. There are empirically supported treatments that can improve psychological symptoms and, therefore, adherence, engagement, and ultimately medical outcomes in patients with pulmonary conditions. The integration of pulmonary rehabilitation and psychological therapies such as CBT may lead to significant benefits for patients, specifically improved emotional functioning, which leads to increased engagement in healthcare and adherence to treatment regimens. Although patients experiencing substantial mental health concerns should be referred to a mental health professional for further evaluation and treatment, this chapter has highlighted various strategies healthcare professionals can utilize when working with patients with pulmonary conditions to facilitate improvement of anxiety and depression symptoms, thereby improving engagement and adherence.

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Chapter 8
Technology to Enhance Engagement in Physical Activity

Stephanie A. Robinson, Thierry Troosters, and Marilyn L. Moy

Importance of Physical Activity and Exercise for Patients with Chronic Lung Disease

Aerobic exercise is important to combat the deconditioning that occurs in patients with chronic lung disease who characteristically experience breathlessness, which leads to a downward spiral of sedentary behavior, physical inactivity, muscle deconditioning, and functional disability [1–4]. Even the smallest incremental increase in exercise can lead to improvements in symptoms. Besides improving or maintaining exercise capacity and minimizing deconditioning, aerobic exercise has additional benefits of improving mood, health-related quality of life (HRQoL), and preventing or managing comorbidities [5]. For specific chronic pulmonary problems, regular exercise can reduce symptoms of dyspnea and pain in COPD [6], help manage

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secretions in patients with cystic fibrosis [7], and aid weight management in patients with asthma [8]. However, due to limited research, the role of exercise in the long-term management of interstitial lung disease and pulmonary hypertension is less clear [9, 10]. Traditionally, pulmonary rehabilitation (PR) has been the standard of care to deliver aerobic exercise in a supervised setting. By reducing overall muscle deconditioning, PR programs minimize symptoms and optimize exercise capacity despite chronic obstructive or restrictive ventilatory deficits [11].

More recently, the focus has shifted from aerobic exercise and has also included lifestyle physical activity (PA), such as walking, and interventions to promote PA that can be brought directly to the patient. Several factors have aided this shift, including the emergence of activity monitors to directly measure parameters such as daily step counts in the home setting [12–14], recognition of the major problem of access to conventional center-based PR programs [15], emergence of mind–body exercise programs [16], and data supporting that every step counts [17–24]. In this chapter, we review the role of technology to promote PA in normal healthy individuals, and then assess its role in addressing access and adherence to PA promotion—to bring PA programs directly to the patients and enhance long-term engagement in PA—in patients with chronic lung disease. Because the most work has been published in the use of technology-based PA interventions in persons with COPD, we focus on COPD and refer to other chronic pulmonary diseases when data are available. Lessons learned in the healthy population and patients with COPD can be applied to other chronic pulmonary diseases.

Persons with COPD with Higher Levels of Physical Activity Have Better Outcomes

Engagement in PA, assessed by questionnaire or directly measured with accelerometry, is a modifiable health behavior that affects COPD-specific outcomes, independent of lung function [17–24]. Even at the early stages of disease, persons with COPD spend significantly greater amounts of time being sedentary, and thus reduced time in PA, compared to healthy subjects [25–27]. COPD is also associated with aging-related comorbidities such as cardiovascular disease, diabetes mellitus, and osteoporosis—all of which may further contribute to functional limitations [28, 29].

Persons with COPD with a higher daily step count have a significantly lower risk of dying, independent of forced expiratory volume in one second (FEV_1) [18–20, 30]. Persons who walk the least at study entry have risks that are 2 and 6 times higher for exacerbations and COPD-related hospitalizations, respectively, compared to those who walked the most over a median follow-up of 16 months [21]. Patient self-report of any moderate to vigorous PA predicted a lower risk of 30-day hospital readmission after an index COPD hospitalization, compared to those who reported no moderate to vigorous PA [22]. These studies of daily step count, of any amount and intensity, support that every step walked can positively impact the disease course [18–24]. Based on these compelling observational studies, the Global Initiative for Chronic Obstructive Lung Disease (GOLD) guidelines recommend regular PA for all persons with stable COPD as standard of care [1].

Limitations of Conventional PR and Need for Technology-Based Interventions to Address Access and Adherence

The current standard of care to promote PA can be broadly separated into (1) PA counseling and (2) referral to conventional, supervised PR (PR) [11, 31]. Brief, episodic general advice to increase PA from a healthcare professional has limited success [31]. Conventional, supervised PR programs clearly reduce breathlessness and improve HRQoL and exercise capacity [11]. Although PR is an integral part of the clinical management of patients with COPD, PR programs face three significant problems: (1) in many regions, most patients who would benefit from PR cannot access it; (2) most patients who are offered to engage in PR prefer not to commit to a program that runs two to three times per week and requires a significant time commitment; and (3) there is no effective strategy to maintain engagement in PA and benefits after patients complete a PR program [32, 33]. Programs are available to only a small fraction of patients with COPD. As outlined by the European Respiratory Society's COPD audit, 50% of European respiratory units have access to PR and only 30% of eligible patients receive PR [34]. The American Association of Cardiovascular and Pulmonary Rehabilitation website lists 561 certified PR programs in the United States for the estimated 16 million Americans diagnosed with COPD [11]. Less than 13% of the potential candidates who would benefit from PR are referred by their healthcare professionals [33, 35]. An analysis of over 33,000 Medicare beneficiaries with COPD from January 1, 2003, to December 31, 2012, showed that only 1,239 persons (3.7%) used PR in 2012, with a dismal increase in utilization of 1.1% over the 10 years [36]. There is geographic disparity in availability since most programs are located at tertiary care centers and require patients to travel to the program 2–3 times a week [35, 37, 38]. This is a significant issue as highlighted in the National Emphysema Treatment Trial, which demonstrated that participants who lived >36 miles from the treatment facility were less likely to complete PR [39, 40].

For those who do complete conventional PR, there is no standardized intervention to maintain PA and thereby the benefits of PR [11, 32, 41–43]. PR programs, typically 9–12 weeks in duration, focus on short-term aerobic fitness and exercise capacity; they do not consistently result in sustained increases in PA assessed by community-based walking [44]. Only 41% of persons described themselves as regular walkers in the year after completion of PR [45]. In the absence of a maintenance strategy to motivate behavior change, gains in exercise capacity and HRQoL diminish toward pre-intervention levels as early as 3–6 months after program completion [11, 46]. These data support that novel interventions are needed to (1) bring exercise programs directly to the patient to improve access to PA promotion interventions and (2) promote engagement in PA and exercise anytime anywhere to maintain adherence to this behavior change over the long term.

Social Cognitive Theory Can Guide Technology-Based Strategies to Enhance Engagement in Physical Activity

A plethora of behavior change interventions have been designed to improve PA not only in healthy adults but also in patients with complex chronic conditions [47]. Many of these interventions have been delivered in face-to-face settings, which can be expensive and inhibit large-scale implementation [48, 49]. Therefore, easily deliverable, efficacious, and cost-effective interventions are needed to improve PA [49]. Technology-based platforms (e.g., internet, mobile devices, smartphone apps, pedometers) are increasingly being recognized as a potentially promising approach to increase PA [50]. These technologies can also be implemented in combination with face-to-face contacts or tele-coaching applications providing a mix of personalized contact and technology support.

Developing and testing best practices to leverage technology to promote PA in pulmonary populations begins with the understanding of relevant theoretical models of behavior change. One frequently adopted model is the social cognitive theory (SCT [51–54], also described in Chap. 6). SCT includes both strategies and constructs on how to educate, empower, guide, and motivate people to adapt health-promoting habits and reduce unhealthy habits [53]. SCT considers both how individuals learn and maintain behavior, and the social environment in which the behavior is performed. Many theories that are used in PA promotion research focus on initiating behavior, with limited consideration to maintaining that behavior [53, 55]. SCT is distinct in that it aims to explain how one regulates behavior to achieve and maintain goal-directed behavior [53].

The key constructs of SCT include (1) self-efficacy, (2) knowledge, (3) outcome expectations, (4) goals, and (5) facilitators and barriers [52, 53]. Self-efficacy is the central construct in SCT because it directly influences behavior, through one's beliefs in his/her ability to apply skills effectively in different situations, and can influence one's goals, outcome expectations, and barriers and facilitators [53, 55]. Knowledge of the health risks and benefits of different behaviors (e.g., risks and benefits of physical inactivity) can impact whether one engages in that behavior. Knowledge of health risks and benefits may encourage possible behavior change; however, these are not sufficient to initiate behavior change [53]. Self-efficacy refers to one's confidence to perform healthy behaviors (e.g., confidence to walk 30 minutes a day). Outcome expectations refer to one's anticipated costs and benefits of different health habits (e.g., expecting to fall or become short of breath during PA). Goals (e.g., walking 3,000 steps a day) and concrete plans for how to achieve those goals (such as joining a walking group that meets weekly) are critical for behavior change. Finally, perceived barriers (e.g., not having the environmental resources to safely walk) and facilitators (e.g., a friend to walk with) can strongly influence behavior change and maintenance [53]. SCT posits that these constructs all interact with one another, known as *reciprocal determinism* [53]. Self-efficacy influences outcome expectations and barriers/facilitators, and all five constructs influence goals. Similarly, all constructs influence behavior and motivation.

Understanding an individual's level of self-efficacy and knowledge, unique outcome expectations, goals, and perceived facilitators and barriers is critical for promoting engagement in PA. Through this understanding, interventions can be tailored to the individual in a stepwise manner [53]. For example, self-efficacy is one of the most consistently identified determinants of PA behavior [56]. If someone has a high sense of self-efficacy and positive outcome expectations for behavior change, they are likely to engage in PA with minimal guidance or support. On the other hand, individuals who are not confident in their ability to engage in PA and expect adverse consequences to engaging in PA will need more supportive interventions that are personalized to their specific barriers [57].

Albert Bandura, the pioneer of modern-day SCT, emphasizes three critical strategies to support the five constructs of SCT—providing social support, goal-setting and feedback, and barrier reduction [53]. Here, we describe how technology can be leveraged to deliver social support, goal-setting and feedback, and barrier reduction strategies, which may be helpful in overcoming common barriers to regular PA in both general and pulmonary populations. Technology also offers the ability to provide patients with continued support for behavior change in between healthcare professional visits. McEwan and colleagues [58] found promising evidence in a systematic review that PA interventions were effective regardless of whether the intervention was delivered in-person, via technology, or using a mixture of the two, suggesting that technology-based interventions, unlike many face-to-face studies, have the added benefit of being accessible anytime, anywhere and improving the reach of these interventions beyond that which can be done in person [58, 59]. We begin by examining literature from general, relatively healthy adults.

Strategy 1: Social Support

Social support, including encouragement and/or competition (e.g., trying to get more steps per day) from friends or family members, can increase engagement and adherence in PA interventions [60–64]. A recent meta-analysis concluded that higher social support specific to PA is associated with greater engagement in PA. SCT suggests that social support is beneficial only if it bolsters self-efficacy [54]. However, social support that fosters social *dependence* can undermine one's ability to cope and can be detrimental to behavior change success [53, 65]. Receiving support from others may pose a threat to one's sense of autonomy and self-efficacy [65]. Thus, it is best to provide social support and guidance that is conducive to self-efficacy enhancement for personal success [66]. For example, before deciding to offer social support, providers of social support should assess recipients' current level of self-efficacy and ask if they would like to be helped. Additionally, providers of social support should be trained to recognize and support recipients' autonomy [65] (e.g., listen to patients, explain how they have taken personal circumstances, concerns, and preferences into account in their recommendations, enable patients to query and if necessary correct their understandings about them, and ensure that patients feel they could choose against the recommendation without jeopardizing their ongoing care) [67].

Social support will be effective only if the user has members within his/her social circle with whom he/she can connect. Many older adults or adults with chronic disease face problems of social isolation, due in part to limited mobility or geographic isolation [68, 69]. As such, interventions that can leverage technology to help connect users to others would be helpful to facilitate social connections and encourage lasting changes in behavior. When using technology in patients, it is advised to verify whether these social networks are secure; for example, ensuring compliance with general data protection regulations in Europe.

Strategy 2: Goal-Setting and Feedback

Goal-setting has been a prominent intervention strategy to increase motivation and effect behavior change. Technology can be used to set automated gradual and realistic exercise goals in interventions that are personalized to the participant. A previous meta-analysis that examined interventions that compared goal-setting to no goal-setting found evidence for a significant increase in PA [58]. The attainment of goals can be enhanced by incorporating feedback, appropriate strategies to help attain said goals, and rewards or incentives [70]. Effective interventions should encourage setting realistic goals; the popular goal to walk 10,000 steps a day is not feasible for everyone, nor is it an evidence-based goal [71]. Gradual, small goals are more effective for long-term engagement compared to larger goals. When people are successful in meeting smaller goals, they can build momentum and over time will be more likely to reach larger goals.

Feedback of goal-achievement is another critical component for maintaining engagement in PA. Feedback can be as simple as letting the patient see their steps in real time (e.g., using a pedometer that displays step counts), or as sophisticated as providing dedicated visual and tailored feedback indicating if one achieved their goal or not (e.g., a website that uses an algorithm to tailor PA goals based on previous activity). Technology can provide feedback as a convenient means for informing, enabling, motivating, and guiding people in their quest to make lifestyle changes. Personalized feedback can be adjusted to participants' efficacy level, unique barriers to their lives, and the progress that they are making. Technology can be leveraged to provide personalized feedback that occurs more frequently than would feedback from a healthcare professional at episodic clinical visits. This personalized feedback may be especially effective in encouraging individuals to monitor their own activity and make behavioral changes [60, 72–74]. The ability to view successful behavior change by tracking one's own activity levels and exercise behaviors can motivate steady progress toward goals, while increasing self-efficacy.

Strategy 3: Barrier Reduction

There are many barriers to engaging in PA, including a lack of time, cost, pain or other symptoms, environmental (e.g., climate or geographical), or lack of enjoyment/willpower [75]. Perceiving certain barriers as insurmountable can foster helplessness; interventions should focus on trying to minimize the patient- and disease-specific barriers to PA. Interventions that specifically try to reduce the perception of these barriers (e.g., perceived lack of time [76]) can increase PA. Based on cognitive behavioral strategies, interventions that reframe or motivate one to overcome barriers (e.g., cognitive restructuring, emotional regulation), misconceptions, and negative expectancies can be successful promoting PA [77]. Technology-based interventions can help participants overcome access barriers such as the time required and/or transportation needed to travel to traditional, in-person PA intervention programs. Additionally, technology can provide easily personalized strategies to help overcome perceived barriers to PA (e.g., too tired, lack motivation, lack skills) [78].

Applying These Strategies in Pulmonary Populations

The use of technology is proving valuable for supporting PA engagement in pulmonary patients. Many of the lessons learned from the large body of research on behavior change and technology-mediated PA interventions in generally healthy adults can be applied to patients living with pulmonary diseases. Along with many of the same psychosocial and behavioral barriers to PA that relatively healthy adults face, barriers to PA in patients with pulmonary diseases are compounded by disease-specific symptoms (i.e., dyspnea, fatigue). SCT can be similarly applied to create technology-based platforms that encourage PA and other self-management behaviors in pulmonary disease. As described above for generally healthy adults, SCT-driven, multicomponent interventions, which combine strategies that foster social support, goal-setting, feedback, and barrier reduction are likely to increase daily PA in pulmonary patients as well [79]. Below, we detail previously published technology-mediated interventions that have been used to promote PA in pulmonary populations and the relevant SCT components that were included in the intervention. Importantly, many of these interventions have utilized more than one of these strategies as a multicomponent intervention. Details as to which components were involved in which interventions are presented in Table 8.1.

Table 8.1 SCT strategies in technology-mediated PA interventions for pulmonary disease

Study	Technology	Population	Intervention component				
			Social support	Goals	Feedback	Barriers	Education
Arbillaga-Etxarri [120]	Website/Pedometer	COPD	✓	✓	✓	✓	✓
Barberan-Garcia [93]	Smartphone/Pedometer	COPD/CHF/Stroke		✓	✓		✓
Choi [122]	Videoconferencing	Lung transplant	✓	✓			
Demeyer [100]	Smartphone/Pedometer	COPD		✓	✓		
Donesky [116]	Videoconferencing	COPD/HF	✓	✓			
Liu [118]	Cellphone	COPD		✓			
Mendoza [123]	Pedometer	COPD			✓		
Moy [98]	Website/Pedometer	COPD		✓	✓	✓	
Martinez[95]/Moy[96, 97]	Website/Pedometer	COPD	✓	✓	✓	✓	✓
Nguyen [84]	PDA/Website	COPD	✓	✓	✓		✓
Nguyen [101]	Cellphone	COPD		✓	✓	✓	
Park [121]	Smartphone	Lung Cancer	✓	✓	✓	✓	✓
Tabak [87]	Website	COPD		✓	✓		
van der Weegen [88]	Smartphone/Pedometer/ Website	COPD	✓	✓	✓	✓	✓
Voncken-Brewster [119]	Website	COPD	✓	✓	✓	✓	
Vorrink [102]	Smartphone/Website	COPD		✓	✓		
Wan [89]	Website/Pedometer	COPD	✓	✓	✓	✓	✓

Strategy 1: Social Support

Patients with pulmonary disease face limitations related to chronic conditions, which may result in social disconnectedness or social isolation [80], making strategies that foster social support potentially even more important for effective PA interventions. In a recent cross-sectional study, social support was significantly related to change in patients' daily step counts [81, 82]. Research that randomly assigned patients with COPD to receive a telehealth self-management intervention found significant improvements in perceived social support and a significant decrease in dyspnea compared to those who did not receive the telehealth intervention [83]. In another trial, researchers utilized web-based education modules with weekly live chat sessions, which were designed to increase peer support in patients with COPD. While COPD patients' perceptions of *general* social support did not significantly increase, participants did report that they felt supported to either start or maintain their exercise programs and significantly increased their duration of endurance exercise per week [84].

Strategy 2: Goal-Setting and Feedback

Setting meaningful and achievable goals facilitates PA in pulmonary patients, as documented in a systematic review of PA interventions [85]. Meaningful goals should be important to the patients. These goals can be based on a patient's functional performance, energy levels, muscle mass, strength, body weight, psychosocial well-being, and resistance to illness, as well as symptoms [85]. Having meaningful goals (e.g., playing with grandchildren) has been identified as a motivator for PR attendance and PA engagement [85, 86]. Along with meaningful goals, goals should be realistic. If a patient with COPD has been walking an average of only 2,000 steps a day, asking them to instantly increase to 10,000 is unrealistic and demotivating. For example, patients with COPD who just completed 3 months of PR were randomly assigned to use a smartphone to track their PA against goals set by a physiotherapist [87]. Interestingly, there was no significant increase in PA [87]. It is possible that because patients had just completed PR and likely already significantly increased their PA, asking them to increase their PA even more was not an attainable goal. Setting such unrealistic goals that patients cannot achieve can be detrimental to their self-efficacy [53].

Providing feedback related to patients' PA goals is an effective intervention strategy in pulmonary patients. In another RCT, "It's LiFe!," a feedback tool was developed that integrated an activity tracker, smartphone, and website for patients with COPD and/or type-2 diabetes that measured activity behavior and automatically generated feedback to the patient and healthcare professional [88]. Patients using the tool engaged in significantly more minutes of exercise a day (approximately 12 minutes) [88]. Goal-setting and feedback are strongly tied to one's self-efficacy. Providing patients with feedback regarding their PA goals provides them with evidence that it is within their power to be more active. Through feedback, successes can build and strengthen self-efficacy, and positive outcome expectations can provide patients with incentives to continue to be active [55]. In a recent RCT, patients with COPD were randomly assigned to receive a web-based intervention that provided personalized goals based on recent activity levels in real time, with a graphical display of step counts to provide patients with feedback in relation to their step-count goal [89]. Compared to patients who were not given the intervention, participants significantly increased their levels of PA [89]. The use of technology provided patient with immediate and visual feedback.

Strategy 3: Barrier Reduction

Usual barriers to PA can be compounded by disease-specific barriers. A systematic review found the following barriers to PA for patients with COPD: coping with changing health status, particularly the limitations of breathlessness and related fear of breathlessness; lack of support and encouragement from others; practical difficulties of access to structured PA intervention programs; and perceived or actual difficulties with the requirements of the programs themselves [85]. In another cross-sectional study, worries about becoming short of breath, needing to use inhalers, and oxygen levels becoming low were the most commonly reported barriers to being active in a sample of patients with COPD [90]. These concerns about becoming short of breath and needing to use an inhaler were significantly related to less PA [90]. Barriers to PA may be related to disease complexity (managing a chronic disease or comorbidities) [85, 86], aging, prior negative experiences with PA or PR, limitations in oxygen therapy [86], or environmental challenges (weather, timing and location of PA interventions, transportation, finance) [85, 86]. A recent RCT of a web-based PA intervention in patients with COPD demonstrated significant maintenance of PA despite barriers due to seasonal variations [89]. Indeed, this intervention did provide content on ways to walk despite bad weather (e.g., on a treadmill or in a mall) [89]. Interventions that do not necessarily increase PA can still be efficacious if they can maintain PA, as delaying the natural or cyclical progression of declines in PA that can occur with chronic disease is critical for health outcomes.

Strategy 4: Disease Education

In addition to the behavior change techniques guided by SCT—social support, goal-setting and feedback, and barrier reduction—patients living with complex chronic pulmonary diseases would also benefit from disease education to help reduce the perception of potential barriers and encourage better self-management. Traditional in-person visits are episodic and do not offer continuous support and education; technology-mediated platforms can help to make disease education and barrier reduction more continuous and supportive. Advancements in healthcare have led to more people living with chronic conditions for longer amounts of time. Increased attention has been placed on developing effective approaches to manage chronic symptoms to maintain patient independence and HRQoL [91]. Approaches to managing chronic conditions are now emphasizing the crucial role that patients play in guiding their own health and disease trajectory [91]. Self-management strategies can be effective across a variety of different diseases, including controlling symptoms and disability, monitoring physical indicators of disease/disability, handling complex medication regimens, adjusting to difficult lifestyle adjustments, engaging in valuable interactions with healthcare professionals, maintaining a healthy diet, and engagement in PA [92]. Therefore, interventions that are developed to enhance self-management behaviors, such as PA, would benefit from incorporating disease and self-management education. Technology can be used to guide patients to take initiative in their healthcare. In a multisite trial, patients with COPD used a smartphone to access tailored and regularly updated disease and self-management information [93]. At one of the sites, patients in the technology-mediated intervention significantly increased and maintained at follow-up how far they walked in the 6-minute walk test (6MWT) by about 8% [93]. In another trial that utilized a website to deliver a dyspnea self-management intervention for patients with COPD, patients received web-based education modules, which resulted in significant improvements in knowledge of dyspnea management strategies [84]. Technology-based strategies, anywhere, any time, and in the comfort of their own home, can educate patients about their disease and proper self-management strategies. This can enable them to take initiative in their own healthcare, thus increasing their sense of self-efficacy and facilitating behavior change [53]. It is important to note the patient's perception of usability (e.g., web interface) is an important predictor of engagement [94]. Therefore, healthcare professionals and researchers alike should involve eHealth specialists to develop effective, usable interventions.

Multicomponent Interventions

Multicomponent interventions that use more than one strategy (e.g., social support, goals and feedback, barrier reduction, disease education) to try to improve participants' knowledge, self-efficacy, outcome expectations, goals, and perceived facilitators and reduced perceived barriers are more effective than interventions that use only one component to try to improve PA [53, 54, 57]. However, as multicomponent interventions can be burdensome and costly, technology can be leveraged to deliver many components at once. One study, Taking Healthy Steps (THS [95–97]), used a website intervention based on the Theory of Self-Regulation, which used goal-setting via a pedometer plus a website that provided individualized step-count goals, iterative step-count feedback, education on disease self-management and motivation, and an online community of social support. Patients with COPD, who used a pedometer paired with the theory-based website intervention, increased their PA by

Upload step-counts from your pedometer and use this interactive graph to review your weekly goal, weekly step-counts, and daily step-counts. Click on the bars in the graph to change from, view by week, to view by day

You met your goal on 5 out of 7 days

Your current goal is 5700 steps per day

Fig. 8.1 This screenshot shows an example of the home page for Every Step Counts, a web-based multicomponent physical activity intervention for COPD. Every Step Counts has shown significant promise for promoting physical activity using the following theoretically driven strategies: social support, goal-setting and feedback, barrier reduction, and disease education. These strategies can support patients' self-efficacy, knowledge, outcome expectations, goals, facilitators, and barriers

778 steps per day and improved HRQoL at 4 months [96]. Similar improvements were seen in another study using the same multicomponent theory-based intervention, Every Step Counts (ESC), which extended THS in an independent and well-characterized cohort with in-person assessments of physiological and psychosocial variables [89, 98]. In a pilot study with a single-arm design, patients who used ESC significantly increased their steps by an average of 1,263 steps per day [98]. In the larger RCT, patients who used ESC increased their average daily steps by approximately 804 steps per day [89]. Figure 8.1 depicts the home page for ESC, which includes multiple components to foster social support (online forum), goal-setting and iterative feedback, barrier reduction, and disease education. Previous research suggests that the minimal clinically important difference (MCID) for steps in COPD ranges from 350 steps/day to 1,100 steps/day [99], indicating that the increases demonstrated in previous multicomponent studies are not only statistically significant, but also clinically meaningful.

Another study utilized a smartphone app to deliver feedback on steps, individualized step goals, text messages, and occasional telephone contact with the research team on an as-needed basis [100]. This semiautomated, pedometer-mediated telecoaching intervention and smartphone app demonstrated significant increases (1,469 steps per day, on average) in PA in patients with COPD [100]. Interestingly, when comparing delivery methods (technology compared to face-to-face), there does not appear to be significant differences in exercise behaviors in those who received a cellphone texting intervention [101] or an internet-based intervention [84] compared to face-to-face interventions, though these interventions were designed to improve dyspnea, with exercise behaviors as a secondary outcome. While effectiveness may not significantly differ, technology-mediated interventions are becoming more pervasive due to their promise of increased accessibility, ease of personalization, and cost-effectiveness.

Important Considerations

Sociodemographic Differences

When developing technology-mediated interventions to promote PA, it is important to consider the target population (e.g., age, health) and the feasibility of using specific technology (e.g., pedometer, website, and app). It is important to design the technology with the user in mind or even together with users in an iterative process (e.g., Vorrink [102]). Previous studies have documented sociodemographic factors associated with mobile health and app use, suggesting that those who are younger, more educated, report excellent health, and have higher income are more likely to use health apps [103–106]. Unfortunately, this population is not the population who could potentially benefit the most from using health technology. Therefore, it is important to consider these sociodemographic differences when identifying appropriate technology-based platforms for PA interventions in chronic pulmonary disease.

Digital Literacy

While technology offers a possible solution to the geographic disparities accessing many face-to-face interventions, there is a risk that they could increase health inequalities due to a “digital divide” in both access to the internet and confidence and skills to use the technology (i.e., digital literacy) [107]. It is also critical that users can easily and consistently sync, view, and understand the information provided by the technology [108]. It helps to involve users in the design of the technology, as they are the ones who will be using it.

Accuracy

Another important consideration is the accuracy of the technology. Pedometers may underestimate activity at a slow speed, as is typical in patients with chronic lung disease. Therefore, accuracy can vary between patients with chronic lung disease and healthy adults [17]. Additionally, significant variation in the accuracy of an accelerometer can be observed based on walking speed [109].

Privacy

Technology can deliver accessible, potentially cost-effective services to promote PA to those who need them most. However, patient engagement with these interventions may face many barriers if the intervention cannot ensure privacy of confidential data, reliable and consistent technology services, usability, and many others [110]. Many technology-based health services rely on cloud computing for data storage. However, some argue that the use of cloud storage poses increased security threats for data transmission and storage [110]. Such privacy concerns are likely to impact some patients' willingness to use technology-based services. Even if we can get patients to use these devices (e.g., Apple Watch or Fitbit), it is imperative that researchers are clear in how to access the patients' data securely. Stakeholders of technology-based services must consider this critical aspect of data storage when attempting to engage patients and implement these services [110].

Future Directions

As technology continues to advance, there is an increasing amount of forthcoming research developing, evaluating, and implementing technology-mediated interventions to promote PA in pulmonary patients. Examining long-term maintenance, Koreny et al. [111] have recently described certain patient characteristics (e.g., engaging in greater levels of PA at baseline, living with a partner, and in a less disadvantaged neighborhood) that predicted adherence to a 12-month intervention. Other avenues being pursued are examining ways to not only increase PA time but reduce sedentary time as well. A recently published trial found a disease-education and self-monitoring intervention using wearable technology feasible and acceptable to reduce sedentary behavior for individuals with COPD admitted to the hospital for an acute exacerbation [112]. Virtual care, or telehealth, is another avenue of technology currently being examined to promote PA in pulmonary patients. In a feasibility study, researchers assessed a tablet-based PA intervention in virtual groups for patients with COPD, with promising findings for increasing PA [113]. Similarly, a recently published protocol aims to compare the efficacy of home-based telerehabilitation to traditional center-based PR in people with chronic respiratory disease [114]. These studies represent just some of the interesting and promising lines of work to look forward to.

Technology to Deliver a Wide Array of Physical Activity Modalities

Walking has gained considerable interest in recent years as a feasible and preferred strategy for increasing PA in many patients. Walking is a free, low-impact activity that can be done practically anywhere and at any time [71]. As such, many technologies are geared specifically toward increasing steps. However, there are other low-impact, accessible activities, such as yoga or Tai Chi (see Chap. 9), that can serve as alternative forms of exercise for health promotion. Compared to PA interventions, these types of activities are structured, timed, and use specific exercises at low intensity. Yoga and Tai Chi are both low-impact activities that emphasize coordination between movement and breath. These activities offer a logical, complementary therapy for pulmonary patients [115–117]. Technology-delivered yoga interventions have been previously assessed in pulmonary patients, though this line of research is limited. A recent study examined the feasibility and clinical outcomes of a home-based yoga program that used videoconferencing (i.e., TeleYoga) to connect patients with COPD and heart failure to live yoga classes [116]. Patients did not demonstrate significant improvement in muscle strength, or the 6MWT distance; however, following performance of the 6MWT, shortness of breath and distress related to dyspnea significantly improved after the intervention [116]. The findings suggest that, despite disease-specific frailty, TeleYoga was a feasible and acceptable method to encourage participation in yoga for cardiopulmonary patients. The benefits of Tai Chi for health are well established; however, to our knowledge, technology-based Tai Chi interventions for pulmonary patients have not yet been developed. Given the benefits of other variations of PA, future work should continue to develop and test theoretically driven, technology-based platforms to promote other types of PA as well. Compared to daily physical activities such as walking, Tai Chi and yoga are unique in that they are typically delivered in a class setting. Videos could be uploaded to a website (e.g., YouTube) to make these classes more easily accessible.

Long-Term Maintenance

Perhaps one of the greatest challenges to encouraging engagement in PA is the long-term maintenance of said engagement. Generally, many technology-based PA intervention studies fail to report follow-up data; as such, little is known about the duration or predictors of maintained engagement in activity. In pulmonary patients, the longest follow-up period appears to be 12 months. There is mixed evidence for long-term maintenance of PA and results are still rather disappointing. Moy and colleagues [97] report on the long-term effects of THS, the website and pedometer-based intervention in patients with COPD at 8 months after a successful 4-month intervention. Although the website was efficacious for increasing daily step counts at the end of the 4-month intervention [96], this increase was not maintained during the subsequent 8-month follow-up [97]. Liu et al. [118] found that patients with COPD increased their walking by about 505 steps following a home-based program at 12 weeks, though these improvements did not persist at 9 months. Similarly, Vorrink et al. [102] did not find significant changes in PA during a 12-month pedometer-based intervention. In their long-term follow-up, Moy et al. [97] also did not find evidence of maintained daily steps in patients with COPD who received a web-based intervention. In another technology-mediated, multicomponent study, researchers did not see any significant changes in PA in patients with COPD [119]. The authors note that only 36% of the intervention group used the technology, citing this as a possible explanation for the nonsignificant effect on PA [119]. Here, the participants were given an option to choose which intervention components they used, though they could have benefitted from more guided and supported use of the intervention components (e.g., instructed where to go and what to look at) [119].

Some studies have documented hope for long-term maintenance of PA. Arbillaga-Etxarri et al. found that patients with COPD who completed a 12-month multicomponent intervention increased their steps by an average of 957 steps compared to baseline. This study utilized an urban training program, which provided participants with feedback, motivation, information, and support via a pedometer, calendar, PA brochure, website, phone text messages, walking groups, and a phone number [120]. Of note, the study was rolled out in Barcelona (Spain) where climate permits walking outside on most days of the year. However, when they examined effectiveness of the intervention by examining all enrolled participants (i.e., intention-to-treat analysis), there were no significant differences in steps between the intervention and control groups. This suggests that this multicomponent, technology-mediated intervention was only successful in improving PA in adherent patients [120]. Perhaps revising the statistical approach, moving away from "average effects" to "responder analysis" and identifying a larger fraction of responders in cohorts of patients using step counters and feedback to maintain PA might shed a different light on findings so far. Since the intervention is relatively cheap for healthcare systems to implement, they can be worthwhile even if they help only a small minority of patients (much like smoking cessation).

As much as it is unlikely to achieve benefits of these interventions in all patients, it is likely that these interventions will lose appeal over time. However, in those patients where the intervention remains a pleasant support and when no exacerbations are encountered, it might be that the intervention is helpful in a fraction of patients. In one study, patients were less likely to be adherent if they had a lower FEV_1/FVC ratio, diabetes, currently smoke, or indicated a greater score on a depression measure [120]. Future research that can identify individual factors that predict long-term response to PA interventions will be helpful to effectively personalize PA interventions.

Long-term maintenance of PA is difficult to achieve in all populations and can be especially difficult in patients with chronic, complex diseases like COPD who face exacerbations and/or comorbidities. It is necessary that PA interventions for pulmonary patients involve healthcare professionals; the use of technology can be instrumental to help clinical teams monitor and motivate patients' PA. Technology is a helpful tool to assist promoting long-lasting changes in PA by allowing healthcare professionals to view cumulative PA data and patterns of increase and decrease, which can be correlated with clinical status. For example, knowing a patient's baseline level of PA can offer concrete guidance to a healthcare professional who is counseling a patient recovering from a COPD exacerbation to increase PA and has a goal to return to a specific known baseline. Activity trackers, apps, and web-based platforms have the capability to integrate multiple theory-based strategies such as social support, goal-setting, and feedback geared to the specific problems of individuals with COPD, barrier reduction, and disease education.

Assessing Technology-Mediated Interventions in Other Pulmonary Populations

The majority of technology-mediated exercise interventions available for pulmonary patients have been confirmed efficacious where COPD is present. Currently, there is a limited amount of work that has explored the efficacy of technology-mediated PA interventions in other pulmonary patient populations. For example, in a recent study, researchers report that a smartphone app–based PR program was effective and feasible to improve exercise capacity (as measured by the 6MWT; patients were able to walk 68 more meters after 12 weeks) in patients with advanced lung cancer undergoing chemotherapy [121]. In another study, researchers piloted a telerehabilitation platform for lung transplant recipients. This intervention included individualized aerobic and strength training plans, video conferencing, and real-time demonstrations of exercises with healthcare professionals [122]. Patients in the intervention demonstrated improved exercise capacity, strength, and steps from pre- to post-intervention. It is important to note that PA programs are not exact substitutes for PR programs. PR programs typically involve more strenuous strength training and target exercise capacity, as opposed to daily PA. Future research would benefit from exploring technology-based interventions to increase PA in other pulmonary populations.

Conclusion

In conclusion, patients with chronic pulmonary disease will benefit from engaging in PA. PA is a significant predictor of health outcomes, comorbidities, and mortality, but engagement in PA can be especially challenging for patients living with a chronic pulmonary disease. Therefore, it is critical to understand best practices to encourage engagement and maintenance of PA. One of the pressing remaining questions is how to effectively encourage these patients to engage in and adhere to PA. Researchers, healthcare professionals, interventionists, and all others seeking to encourage PA promotion should incorporate theory- and evidence-based decisions that will foster patients' knowledge, self-efficacy, outcome expectations, goals, and perceived facilitators, and reduce perceived barriers to PA. When developing and recommending interventions, multiple components should be leveraged to increase patients' adherence to the intervention, and ultimately their chance for success. For example, a clinical team could present a suite of possible options to support behavior change in patients and allow patients a choice or the possibility to choose another approach if a first approach is not leading to the anticipated outcome. This is common practice in other behavior change interventions such as smoking cessation or weight loss interventions.

Technology offers a unique method to deliver multicomponent, efficacious interventions to encourage PA, but it is acknowledged that technological solutions are not one size fits all. Understanding how to utilize technology to effectively encourage PA is critical. Similarly, it is necessary to understand who will benefit the most from which intervention. Sociodemographic (e.g., age, education, income, health status) and other individual differences (e.g., self-efficacy) can significantly impact the efficacy of an intervention and should be carefully considered. Other caveats to consider when leveraging technology to promote activity are the potential threats to data privacy and security, as well as threats to accuracy and reliability. The potential benefits of using technology to encourage PA in pulmonary patients outweigh many of the addressable cons. Future research and intervention development will benefit from assembling teams of consultants who are well equipped to address these important considerations, such as eHealth experts.

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Chapter 9

The Role of Mind–Body Approaches in Promoting Healthcare Engagement and Positive Behavior Change

Kristen M. Kraemer, Christina M. Luberto, Daniel L. Hall, and Gloria Y. Yeh

Introduction

Since ancient times, the relationship between mind and body has been a subject of philosophical debate and interest, from Cartesian concepts of mind–body dualism to advances in psychoneuroimmunology to present day "mind–body medicine." Over the last half century within healthcare, we have seen a re-emergence of the mind–body connection and the recognition that mind and body are inextricably linked. With the biopsychosocial approach, there is now a deeper appreciation for mind–body interactions and the potential role for mind–body interventions (MBIs) in healthcare.

According to the National Institutes of Health (NIH), mind–body medicine focuses on "the interactions among the brain, mind, body, and behavior, and on the powerful ways in which emotional, mental, social, spiritual, and behavioral factors can directly affect health" [1]. MBIs may include a wide range of behavioral therapies, including meditation, relaxation techniques, guided imagery, Tai Chi, qigong, and yoga. There is also important overlap with psychological behavioral interventions, such as cognitive behavioral therapy and acceptance and commitment therapy. MBIs have been touted as relatively safe, low risk, low cost, and promoting self-care where patients can take a more active role in their treatment. As a whole,

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they have been studied extensively in multiple clinical populations, from cardiovascular disease, cancer, neurological disorders to mental health, musculoskeletal conditions, and chronic pain, with benefits in psychological well-being, physical function, and objective physiology [2–6]. In pulmonary populations, there has been particular interest in movement-based mind–body therapies, mindfulness meditation, and mind–body breathing for patients with chronic obstructive pulmonary disease (COPD) and asthma [7–9]. Mechanistic research has provided scientific understanding of mind–body interactions involving the central nervous system, autonomic nervous system, and endocrine, immune, and cardiopulmonary systems that provide potential pathways by which MBIs may influence health [10–13].

As such, a large and growing body of literature provides empirical support for MBIs to promote healthy behaviors and healthcare engagement. Recent large-scale NIH initiatives to elucidate the science of behavior change have identified key mechanistic areas of focus – including self-regulation, stress and resiliency, and social interactions – all of which are highly relevant and impacted by MBIs [14].

In this chapter, we will introduce MBIs alongside a conceptual model of how particular constructs involved in MBIs may impact health behavior change and healthcare engagement in pulmonary patients. We then summarize the relevant evidence supporting the use of MBIs for promoting effective healthcare engagement (particularly medication adherence) and for promoting two important lifestyle behaviors often emphasized in the care of pulmonary patients (i.e., smoking cessation and physical activity). Throughout this chapter, relevant studies in pulmonary populations are highlighted when available. We conclude by outlining practical considerations and suggestions for referring pulmonary patients to MBIs.

Mind–Body Interventions: A Heterogeneous Group of Modalities That Share Common Elements

Most MBIs are inherently multimodal, often utilizing cognitive tools (e.g., meditation or imagery), breathing techniques or awareness of breath, and physical movement or postures. For example, Tai Chi is a mind–body movement therapy with origins in Chinese martial arts that incorporates low-impact exercise, slow and fluid body movements, with meditation, breath, and body awareness. While still practiced by many as a martial art, it has gained popularity as a health-promoting exercise that is easy to engage in and accessible to even the most deconditioned. Similarly, yoga is a mind–body movement therapy with origins in ancient Indian philosophy. While traditionally it was developed as a spiritual, philosophical discipline or way of life, modern-day yoga in the United States is characterized as a gentle exercise form that incorporates stretching, postures, meditation, and breathing techniques. On the other hand, formal meditation is typically a seated practice, although meditation can be incorporated into any activity, such as walking.

All meditation practices incorporate self-observation of mental activity and physical sensations, attentional focus training, and cultivating an attitude of acceptance. For example, the techniques in mindfulness meditation teach attentional control at the current moment with nonjudgmental acceptance by focusing on observation and nonreactivity to events generated internally (bodily sensations, breath, thoughts, and emotions) and externally (sights, sound, and taste) [15]. Many meditation techniques are rooted in traditional Buddhist or Taoist philosophies, although meditation practices have been successfully secularized and used widely in the United States, Europe, and Australia [16].

Contributing to the heterogeneity of MBIs is the fact that within each MBI, there may be multiple different styles. For example, Yang style and Chen style are two different Tai Chi lineages; Vinyasa yoga may be more fast-paced than Hatha yoga. In general, these styles may differ in choreography or postures, emphasis on breathing or meditative elements, or other focus of attention. In loving-kindness meditation, as opposed to other mantra meditations, the focus is on generating unconditional kindness to others and self. The breathing component of MBIs can be diverse. Most mindfulness-based interventions cultivate simple breath awareness. However, some relaxation-based practices may instruct breathing in a certain way, or certain rate, or otherwise try to change the breathing pattern. Over the last two decades, formal, standardized mind–body programs have been developed, which have facilitated both research and clinical implementation. One of the most studied and well-known programs, Mindfulness-Based Stress Reduction (MBSR), is an 8-week program of mindfulness meditation, body awareness, and yoga implemented in a group setting with a trained instructor [16]. Subsequent adaptations of MBSR have been developed for a variety of conditions, such as Mindfulness-Based Cognitive Therapy (MBCT) for depression [17].

Despite this vast heterogeneity of mind–body approaches, there are a few simple, core elements that are commonly shared in most interventions. One important core element is mindfulness, defined as a state of active and open attention/awareness to the present moment, or the ability to attend in a nonjudgmental way to one's own physical and mental processes during everyday tasks [15]. The second is an attention to the breath/breath awareness, which has particular relevance to pulmonary populations since ease of breathing is a common goal of pulmonary treatment. Most often in MBIs, the breath is used as an easily accessible focus of mindful attention. A third core element shared between interventions is an explicit self-care nature. These are patient-centered practices that inherently acknowledge the patient's role in his/her own healing and self-management. Congruent with patient-centered care principles, the patient can be an active participant in his/her health, fostering self-efficacy and sense of control. With this self-care nature, MBIs align well with the biopsychosocial approach that emphasizes the need to address not only the physical illness burden but also mental and psychosocial suffering that equally impact the patient experience.

Mind–Body Conceptual Model: Constructs Relevant to Pulmonary Healthcare Engagement and Positive Behavior Change

Figure 9.1 illustrates a conceptual model of how MBIs, as a broad diverse category of therapies, can impact pulmonary healthcare engagement and health behaviors, and thus downstream health outcomes. Several lines of clinical and mechanistic inquiry support the potential for MBIs to modulate salient neurocognitive [18, 19], psycho-emotional [20], and biophysical processes, and further recognize the interrelationships and interactions between individual processes across domains. Table 9.1 summarizes the key elements that we posit within each of the three domains and their relevance to the pulmonary patient. These processes broadly impact self-regulation, defined as the ability to manage and guide oneself in the pursuit of a goal, which can act to promote effective health behavior change and pulmonary healthcare engagement [21].

Within the neurocognitive domain, most MBIs instruct individuals to practice paying attention to the details of their present moment experiences, which includes

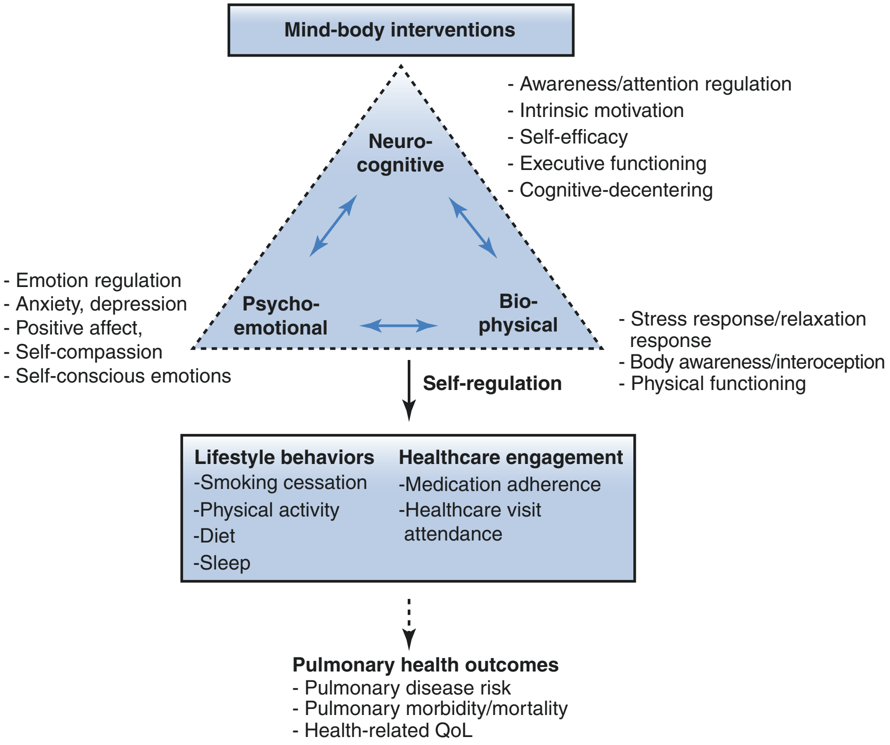

Fig. 9.1 Conceptual model: how mind–body interventions may impact pulmonary healthcare engagement and behavior

Table 9.1 Neurocognitive, psycho-emotional, and biophysical constructs involved in mind–body interventions and the relevance to pulmonary healthcare engagement

Construct variables	Definition	How it may influence pulmonary healthcare engagement
Neurocognitive domain		
Mindful awareness Attention regulation	Ability to notice events (internal and external) as they occur, with openness, curiosity, and nonjudgment Ability to place attention, sustain, and shift it as needed in a given moment	• Cultivates the ability to recognize effects of stress on the mind and body (e.g., awareness of the anxiety-breathlessness cycle) • Promotes early awareness of symptoms that might be problematic (e.g., recognizing when to seek help, rest, or call the clinic) • Promotes purposeful action and informed decision-making about self-care (e.g., pausing before using rescue inhalers to prevent overuse, recognize the role of cravings in smoking cessation) • Helps turn attention away from distractions and barriers, stay focused on healthcare goals (e.g., focus on the benefits of seeing the healthcare professional versus the transportation challenges of getting to the hospital)
Intrinsic motivation	Feeling moved to engage in a behavior due to internally driven factors and the value of the behavior itself, not due to an external reward	• Makes patients more likely to take an active role in their healthcare because doing so is personally meaningful to them (e.g., patients believe it is important to quit smoking, the motivation to exercise is because it is enjoyable and feels good)
Self-efficacy	Confidence in one's ability to execute a desired behavior	• Increases the likelihood of initiating and maintaining engagement in health behaviors (e.g., participation in pulmonary rehabilitation, physical activity, and self-care)
Executive functioning	Higher level cognitive processes such as working memory, planning, and learning	• Promotes the ability to organize and set goals and remember to adhere to these goals (e.g., complex medication regimen adherence, visit attendance, and exercise plan) • Helps patients make calm, rational decisions about how to best take care of themselves (e.g., setting an intention to take medications as prescribed)
Cognitive decentering	Ability to notice thoughts as transient mental events rather than necessarily true facts that must be acted upon	• Allows patients to recognize and disengage from unrealistic and unhelpful thoughts about their healthcare (e.g., "If I go see the doctor, he might tell me I have cancer," "I don't really need another pulmonary function test," "It's fine if I have just this one cigarette")

(continued)

Table 9.1 (continued)

Construct variables	Definition	How it may influence pulmonary healthcare engagement
Psycho-emotional domain		
Emotion regulation Anxiety, depression Positive emotions/affect	Ability to effectively modulate emotional experiences Feelings of nervousness or tension, sadness, or loss of pleasure Feelings of happiness or contentment	• Promotes the ability to overcome uncomfortable emotions that otherwise interfere with engagement (e.g., managing anxiety so that it does not lead to avoidance of medical visits or tests) • Reducing anxiety and depression symptoms reduces barriers to medication adherence and positive health behaviors (e.g., smoking cessation and physical activity)
Self-compassion	Feelings of acceptance, understanding, and kindness toward oneself in the face of suffering or failures	• Enhances motivation to be gentle and caring to oneself and engage in positive health behaviors (e.g., physical activity) • Allows healthy acceptance of setbacks and provides positive understanding toward trying again (e.g., I am not a failure because I fell off my diet or exercise regimen)
Self-conscious emotions	Feelings of guilt, embarrassment, or shame	• Maladaptive stigma-related emotions may cause self-blame, devaluing, and feelings of unworthiness (e.g., “It is my fault I have COPD because I smoke, I don’t deserve to get better, see the doctor, or have others care for me) • Reducing these emotions can lead to fewer anxiety and depression symptoms, decreased avoidance of healthy behaviors
Biophysical domain		
Stress response/ relaxation response	Stress-related physiology involving the hypothalamic–pituitary–adrenal axis, autonomic nervous system, and immune function Opposite ends of the stress/ destress spectrum	• Stress may contribute to symptoms (e.g., increased dyspnea and anxiety) that either prompt (e.g., adherence to inhaler) or prevent certain health behaviors (e.g., physical activity) • Mind–body techniques may enable patients to stay calm in stressful situations (e.g., during pulmonary function tests, when discussing test results, and during episodes of dyspnea in daily activities)
Body awareness/ interoception	Awareness of the internal physiological state of the body Ability to notice body sensations as they occur, with openness and nonjudgment	• Allows patients to notice physical symptoms that can then be reported to healthcare professionals for appropriate management (e.g., changes in breathing patterns and side effects of medications) • Allows awareness of the positive physiological effects of self-care interventions (e.g., increased energy, decreased dyspnea with daily walking, and proper medication use)

Table 9.1 (continued)

Construct variables	Definition	How it may influence pulmonary healthcare engagement
Physical functioning	Ability to complete daily activities Related measures such as fatigue, strength, flexibility, balance, sleep, and pain	• Increased physical strength and energy may promote engagement in physical activity and attendance at medical visits due to greater ease leaving the house and traveling • Better physical function can feedback on self-efficacy and confidence to engage in healthy behaviors

noticing when the mind wanders or becomes distracted and gently redirecting attention back to the present moment. This cultivates mindful awareness and attention regulation [19]. The ability to be aware of present moment experiences in daily life, and notice these experiences with openness and nonjudgment, is defined as trait mindfulness [22, 23]. Greater trait mindfulness has been correlated with better planning behavior, increased self-efficacy, and intrinsic motivation [24, 25]. An individual who is intrinsically motivated may engage in a behavior because he/she finds it inherently enjoyable, as compared to extrinsically motivated by an outside source [26]. Intrinsic motivation is widely associated with more successful engagement in a variety of health behaviors [27]. Enhanced self-efficacy refers to an individual's confidence in his/her ability to successfully execute a desired behavior and can greatly influence behavior initiation and maintenance [28].

MBIs also impact executive functioning, including planning behavior, cognitive flexibility, learning, and working memory capacity [29, 30]. A meta-analysis of 11 studies reported the potential for Tai Chi to enhance cognitive function in older adults, particularly in the realm of executive functioning and in individuals without significant baseline impairment [31]. Another key cognitive skill targeted by MBIs is cognitive decentering, the ability to view thoughts as transient mental events, with the understanding that thoughts are separate from the self and not necessarily true or worthy of action [32]. Individuals become able to recognize unrealistic or unhelpful thought patterns, particularly repetitive thinking patterns such as worry and rumination, and develop skills to disengage from these thoughts (e.g., by redirecting attention to other aspects of the present moment).

In the psycho-emotional domain, MBIs can enhance emotion regulation and mood [33]. Emotion regulation is the ability to effectively modulate emotional experiences (e.g., managing anxiety and not becoming overwhelmed during a pulmonary visit) [34]. Empirical work strongly suggests that emotion regulation difficulties contribute to the development and maintenance of anxiety and mood disorders [34]. Multiple studies suggest that MBIs enhance emotion regulation skills and improve anxiety and depressive symptoms [6, 20, 35–43]. In one study, patients with COPD who underwent a 6-month qigong program demonstrated greater self-reported improvements in the ability to modulate distress compared to those in a self-management exercise group or control group [38]. Other studies have shown that mindfulness training may improve anxiety, depression, and emotional functioning in chronic pulmonary conditions (e.g., COPD, asthma, and lung cancer) [40–43]. MBCT combined with pulmonary rehabilitation has also been associated with greater reductions in anxiety and depressive symptoms compared to pulmonary rehabilitation alone [40]. Another randomized controlled trial (RCT) of a mindful yoga program reported improved mood symptoms, including dyspnea-related distress among individuals with COPD [44]. Impaired mental health and mood disorders can be barriers to positive healthcare engagement. For example, individuals who are unable to effectively regulate emotions are more likely to engage in negative health behaviors (e.g., smoking) [45].

Self-compassion, another key emotional process that may be impacted by MBIs, involves fostering feelings of kindness and understanding toward oneself, recognizing that one's experience is part of a larger human condition, and holding difficult internal experiences in mindful awareness [43, 46–48]. This may be particularly relevant for patients dealing with personal barriers and setbacks when trying to engage in and maintain behavior change [48]. Negative self-conscious emotions and stigma-related effects are another area that may be modulated by MBIs. Individuals with chronic medical conditions may be especially prone to experience self-conscious emotions, including guilt, shame, and embarrassment [49–51]. A recent mixed-methods study demonstrated that individuals with COPD experienced higher levels of self-conscious emotions than healthy controls, and these emotions were associated with elevated anxiety and depressive symptoms [49]. Stigma-related barriers to healthcare engagement may be important in pulmonary patients, such as those with COPD or lung cancer, who are often stigmatized by their prior history of smoking and a sense that they "brought this on themselves." In lung cancer more specifically, stigma is associated with increased psychological distress, poor HRQoL, poor medication adherence, and decreased help-seeking [52, 53]. Mindfulness training has been shown to attenuate the negative effects of stigma in other medical populations [54, 55], and thus, one might hypothesize the potential for MBIs for pulmonary patients.

Within the biophysical domain, MBIs are known to decrease the stress response and modulate neuroendocrine physiology and the balance between the sympathetic and parasympathetic nervous system [10, 56]. Studies have shown that greater stress responses are associated with higher likelihood of maladaptive coping and health-harming behaviors, such as smoking, alcohol, and overeating [57]. Many MBIs have been shown to reduce sympathetic nervous system activity and elicit the relaxation response (the opposite of the stress response, characterized by decreased oxygen consumption, heart rate, and respiratory rate) [56, 58, 59]. Others have demonstrated improvements in neuroendocrine stress markers, such as catecholamines, renin activity, basal skin conductivity, and C-reactive protein [10, 60].

Body awareness and interoception are further skills that are cultivated through many MBIs. Interoception is defined as the body-to-brain axis of sensation and awareness of the internal physiological state of the body. These perceptions of bodily signals are inherently influenced by, and interact with, cognitions and emotions. Theories of embodied cognition describe this bidirectionality of top–down and bottom–up processes, whereby cognitive processes are modulated by perceptions of sensorimotor states, and interoceptive representations of body states are profoundly associated with emotional experience and cognitive functions [61]. Preliminary findings suggest that MBIs may improve body awareness in chronic medical conditions (e.g., chronic pain) [62]. In one qualitative study, individuals with COPD reported enhanced body awareness following a yoga intervention [63]. The effects of MBIs on body awareness in pulmonary conditions may be a promising area of future research.

Finally, a number of physical function outcomes have also demonstrated improvement with MBIs [64–68]. For example, meta-analyses have shown that MBIs are effective for improving pain across several populations [64, 65]. It is purported that the ability to relate to painful sensations in a nonjudgmental, accepting manner, instead of fighting them, may lead to better pain-related outcomes. In addition, improvements in strength, flexibility, balance, self-reported functional status, and fatigue with active MBIs, such as yoga or Tai Chi, have been shown across multiple medical populations, including in COPD and lung cancer [65–71]. MBIs may also improve sleep function [72–74]. While those with barriers and impairments in these common physical function measures may be more likely to engage in negative health behaviors, improvements in these measures may beneficially feedback on overall functional status, emotional health, and self-efficacy [75]. These may all promote the ability to engage in self-care and positive health behaviors.

As suggested in the conceptual model (Fig. 9.1 and Table 9.1), processes within one domain may additionally promote or interact with processes within the other domains and exert overall positive biofeedback effect on healthcare engagement and important health behaviors. A growing literature of neuroimaging studies has also helped to anchor various MBIs to particular neural substrates within these domains. For example, a meta-analysis reported several consistent brain regions involved in meditation, including the insula (e.g., important in interoception and body awareness), frontopolar cortex (e.g., meta-awareness and higher order cognition), hippocampus (e.g., memory), medial prefrontal cortex (e.g., social cognition and behavior), and anterior/mid-cingulate cortex (e.g., emotion regulation) [18].

One salient illustration of the complex interplay between interoception, cognition, emotions, and physical symptoms is the well-known anxiety-breathlessness cycle [76]. Initially described in COPD, this paradigm is relevant to any pulmonary population with dyspnea as a significant symptom, including asthma, COPD, interstitial lung disease like pulmonary fibrosis, cystic fibrosis, and pulmonary hypertension. Figure 9.2 shows the cycle whereby emotions, dyspnea, complex behavioral responses, and disease pathophysiology are interrelated and feedback on each other through a vicious cycle that results in a spiraling and worsening of symptoms. MBIs may cultivate an awareness over time that allows this cycle to break [77]. At the simplest level, nonjudgmental, mindful awareness, and interoception promote the recognition of bodily sensations, yet without

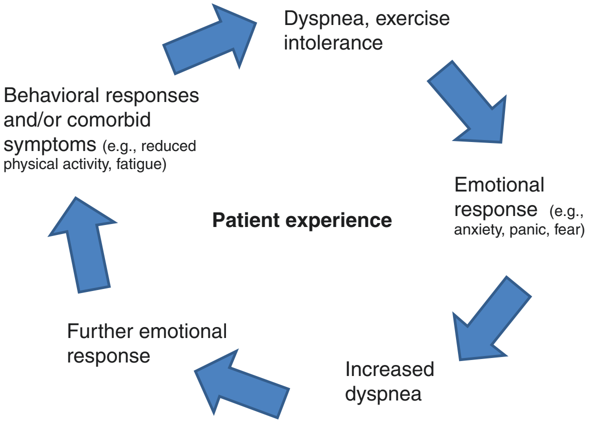

Fig. 9.2 Anxiety-breathlessness cycle. The cycle starts with disease pathophysiology leading to dyspnea, which then exacerbates anxiety and emotional responses, which then leads to more dyspnea, further exacerbating emotional dysfunction, comorbid symptoms, or behavioral responses (e.g., fatigue and reduced activity). This leads to worsening disease state, which manifests as increased dyspnea, and the cycle continues. (Reprinted with permission from Yeh and Horwitz [77])

harmful reactivity or catastrophizing. This leads to lessened anxiety in the moment, which further supports an improvement in symptoms and anxiety-related dyspnea. This then leads to continued physical activity, further supporting improved symptoms over time.

The development of intrinsic motivation and self-efficacy for physical activity is particularly relevant in sedentary patients with chronic lung disease and can help patients initiate and maintain an exercise program to alleviate deconditioning and improve endurance and overall health. Meditative movement, such as Tai Chi, yoga, and qigong, may be suitable forms of exercise for deconditioned patients with chronic pulmonary disorders. For those unable or otherwise unwilling to engage in conventional exercise, mind–body exercises can serve as “gateway” exercises, as a bridge to higher intensity exercises or as a low-impact alternative. In addition, patients with pulmonary conditions may struggle with negative thoughts that are barriers to self-management (e.g., “I don’t really need to take my inhalers” or “I’ll never be able to do any exercise” or “It is my fault that I have COPD, so I don’t deserve to get better”). MBIs can cultivate the ability to notice and disengage from unhelpful thoughts. MBIs can also allow patients through embodied cognition to become more self-aware of, for example, musculoskeletal patterns related to pain, dyspnea, anxiety, or positive emotions, confidence, and bodily comfort, which then foster self-care and self-regulation. On a basic level, improved executive function and working memory may directly support health behaviors, such as pulmonary medication and inhaler adherence, oxygen use, use of noninvasive ventilation, adherence to medical visits or tests. Finally, treatment of common global symptoms with MBIs, such as dyspnea, fatigue, insomnia, and depression, may all have downstream benefits that impact adherence and motivation toward self-care.

Healthcare Engagement

The central premise of promoting healthcare engagement is that patients who are more effectively engaged in their healthcare experience have better health outcomes. Healthcare engagement can have both benefits and costs to patients, such that both under- and overutilization can be detrimental. *Avoiding* healthcare engagement (e.g., not following through with symptom monitoring, delaying follow-up visits or recommended screening, or lack of adherence to medication) may place patients at risk for not detecting disease, progression, or additional health conditions, thereby worsening clinical outcomes and increasing healthcare costs [78–81]. For example, underutilization of cancer screening may increase the risk for both cancer-related and noncancer-related deaths [82]. Conversely, patients who *seek reassurance* through frequent healthcare engagement (e.g., unscheduled visits or communication with doctors, requests for tests) may be at risk for poorer emotional, physical, and financial outcomes due to excessive travel, costs, or side effects from unnecessary procedures [83–85].

MBIs may be particularly suited to address the self-regulatory factors that influence initiation or maintenance of healthcare engagement. Greater self-awareness of thoughts, sensations, and feelings cultivated through MBIs is associated with greater uptake of healthcare services [86]. Perceptions of benefits and risks of treatments, anticipated regret, self-efficacy, and self-conscious emotions including stigma and shame may all interfere with or promote the engagement of healthcare [87]. Maintenance of effective healthcare engagement requires patients' continued reassessment, awareness, and self-regulation.

Medication Adherence

One concrete area within healthcare engagement that may be impacted through MBIs is medication adherence. In a model proposed by Salmoirago-Blotcher et al., mindfulness training can lead to improvements in attention, working memory, sleep quality, and depressive symptoms, which may then beneficially impact medication adherence, and thus improve downstream biomarkers and clinical outcomes [88]. Direct evidence of mind–body therapies affecting medication adherence in pulmonary populations, however, is relatively lacking. Most data in this area are focused on patients with human immunodeficiency virus (HIV), a population among which poor adherence to antiretroviral therapy is well documented [89]. In one recent pilot RCT, in HIV-positive youth, those who took part in MBSR reported higher levels of mindfulness, problem solving, and life satisfaction, as well as lower levels of aggression and viral load thought due to improved medication adherence [90]. In another study, qualitative interviews with HIV-positive youth [91] identified that MBSR addressed social stigmas and stress by allowing nonjudgmental awareness, acceptance, new understanding, and acceptance of illness, which patients reported as helping to facilitate greater medication adherence. A larger RCT of mindfulness on medication adherence among HIV-positive youth is currently underway (ClinicalTrials.gov NCT02624193).

The promise of MBIs for medication adherence has been examined in a few other populations that might be extrapolated to pulmonary populations [92–95]. One cross-sectional study in patients with mild symptoms of Alzheimer's disease reported a positive relationship between social support, family satisfaction, awareness of disease, and medication adherence. Mindfulness partially mediated the relationship between disease awareness and medication adherence [95]. In patients with diabetes, mindfulness may impact adherence to a diabetic diet, physical activity recommendations, and adherence to complicated medication regimens, frequent glucose monitoring and insulin injections [93]. Specifically, in a pulmonary population, an ongoing RCT in patients with COPD is examining the impact of a brief multimodal MBI on use of noninvasive ventilation [96]. Noninvasive ventilation in patients with COPD may improve patient outcome, decrease hospitalizations, and decrease exacerbations in patients with chronic hypercapnia [97]. While it is often started in the hospital, adherence at home is poor (see Chap. 12). The study investigators hypothesize an increase in adherence to noninvasive ventilation in patients who received a brief psychological support intervention, including counseling, relaxation, and mindfulness-based exercises when compared to a standard care control [96].

Health Behavior Change: Smoking Cessation (see Chap. 14)

Research suggests that MBIs are a promising approach to smoking cessation among a general population of smokers. One of the first seminal trials was an RCT by Brewer and colleagues [98], which found that eight sessions of mindfulness training (1.5-hour sessions twice per week for 4 weeks) led to significantly higher abstinence rates as compared to the American Lung Association's Freedom from Smoking educational program (i.e., 31% vs. 6% abstinence rates at 17-week follow-up, respectively). Additional trials of similar interventions also found significantly higher abstinence rates with mindfulness training as compared to educational programs [99] and as compared to usual care [100–102]. Many studies have been based on the standardized MBSR program, involving training sessions over 8 weeks and daily at-home mindfulness practice. Not all studies have shown positive results, however, and the literature includes trials of variable quality, intervention structure, delivery medium, control group, timing of outcomes, and population characteristics [103].

In a recent RCT of over 300 smokers, those who learned mindfulness skills using a smartphone application were better able to resist smoking urges and refrain from smoking when experiencing cravings [104]. A small pilot trial of an 8-week Vinyasa yoga intervention as compared to health education for women smokers found significantly higher post-intervention abstinence in yoga (47%) versus health education (17%) [105]. A follow-up qualitative study revealed that women reported using yogic breathing to cope with cravings and stress, and that yogic breathing was also helpful for improving relaxation, body awareness, and general well-being [106]. These findings suggest that yoga practices and breathing skills, in particular, may provide smokers with healthy strategies to cope with cravings and minimize smoking, with additional benefits for overall well-being.

Mechanistic Pathways to Smoking Cessation

There are well-described theoretical models for how MBIs may promote smoking cessation and a significant amount of evidence to support these models. In line with our conceptual model (Fig. 9.1), theoretical models of MBIs for smoking cessation suggest that mind–body training can target cognitive and emotional processes, such as repetitive thinking, cognitive decentering, emotional regulation, and trait mindfulness, to help smokers notice triggers, resist cravings, and prevent smoking behavior [107]. Indeed, greater trait mindfulness among smokers has been associated with better emotion regulation, lower levels of nicotine dependence, fewer withdrawal symptoms, and greater self-efficacy for quitting [108, 109]. Laboratory-based studies indicate that mindfulness training decouples the typical relationships between negative emotions, smoking urges, and smoking behavior [110]. That is, while smokers typically experience strong cravings to smoke when they are upset, mindfulness training reduces the urge to use smoking as a coping strategy and helps people resist smoking even when experiencing cravings. Improvements in the ability to tolerate negative emotions and "decenter" from unhelpful thoughts likely underlie these benefits [107]. In a small qualitative study of college students with experience with Tai Chi, increased awareness of smoking habits was found to be one way Tai Chi exercise can promote smoking cessation [111], providing preliminary evidence that other MBIs may also reduce smoking behavior by targeting cognitive–behavioral processes.

Despite these promising findings and the importance of smoking cessation among patients with pulmonary conditions, there have surprisingly been no studies of mind–body smoking cessation interventions conducted specifically in pulmonary patients. This is an area ripe for future research.

Health Behavior Change: Physical Activity (See Chap. 8)

Rates of physical inactivity are alarmingly high among individuals with pulmonary conditions, particularly COPD [112]. Numerous consequences of a sedentary lifestyle for patients with COPD are well known, including higher rates of acute exacerbations, hospital admissions, and mortality [113–117]. MBIs may promote physical activity by fostering self-regulatory skills and self-awareness.

Physical Activity Levels

Studies in multiple medical populations have examined the effects of MBIs on self-reported (e.g., physical activity recall) and objective (e.g., accelerometer) indices of physical activity [118, 119]. In a recent meta-analysis of RCTs among overweight or obese individuals, mindfulness training (i.e., one session to 24 weeks of skills training) evidenced a small-to-medium effect on self-reported physical activity levels from baseline to post intervention [120]. Acceptance-based training (i.e., one session to 24 weeks of skills training), which aims to foster acceptance of present-moment internal experiences, has been associated with improvements in self-reported and objective physical activity levels across several populations [121].

In recent years, there has been a lot of interest in mind–body movement, such as qigong and Tai Chi for COPD. As with any exercise, studies suggest that consistent and continued practice is important for sustained benefits. Some studies suggest a role for mind–body exercises as adjuncts to conventional pulmonary rehabilitation [8, 122–124]. Overall, safety data are very good; multiple pilot studies have demonstrated the feasibility and safety of mind–body exercises in patients with pulmonary conditions [71, 125]. Following Tai Chi interventions (e.g., 12-week programs), individuals with various medical conditions have demonstrated improvements in indices of objective moderate-to-vigorous and self-reported physical activity [126–128]. These include studies in older adults and deconditioned patients with chronic heart failure, populations that share common characteristics with chronic pulmonary conditions like COPD. Preliminary findings suggest that gains in physical activity engagement may be maintained up to 3 months following Tai Chi [126]. Some observational studies suggest that yoga practice is associated with higher rates of nonyoga physical activity, including more moderate-to-vigorous physical activity (e.g., biking, aerobics, and fast-paced walking) [129], although not all are positive [130]. In one RCT among sedentary adults, a 10-week yoga program was associated with increases in physical activity levels post intervention (assessed via 7-day Physical Activity Recall) [131]. Some studies suggest that improvements may be maintained over time for up to 6 months [66].

Cardiorespiratory Fitness and Lung Function

Condition-related factors, including severity of symptoms and level of disability, have been identified as barriers to exercise adherence in cardiopulmonary populations [132]. For example, lower forced expiratory volume in 1 second (FEV_1) predicts poorer adherence to an exercise program 1 year following pulmonary rehabilitation [133]. MBIs may help to improve cardiorespiratory fitness and lung function among individuals with pulmonary conditions [8, 124]. In a meta-analysis of 16 studies of patients with COPD, meditative movement (e.g., yoga and Tai Chi), compared to nonexercise control conditions, was associated with improvements in exercise tolerance (6-minute walk distance), FEV_1, and FEV_1% predicted [134].

These improvements in lung function are hypothesized to involve more efficient breathing (e.g., lower oxygen consumption, reduced breathing frequency, modulation of airway reactivity, and improved blood oxygenation without an increase in minute ventilation) and improved respiratory muscle strength [134]. Across additional meta-analyses, individuals with COPD who participated in yoga, Tai Chi, and qigong evidenced significant improvements in exercise tolerance and lung function when compared to nonexercise controls [134, 135]. Among individuals with asthma, yoga, compared to usual care, was associated with improvements in symptoms, FEV_1, and FEV_1/FVC, although risk of bias in many studies was unclear [9].

In patients with chronic heart failure, a higher risk cardiac population that shares features with COPD including the cardinal symptoms of dyspnea and exercise intolerance, studies have found cardiorespiratory benefits of MBIs. For example, a 12-week Tai Chi program, compared to usual care, was associated with an increase in exercise tolerance among individuals with chronic systolic heart failure [136]. Preliminary findings from a small RCT in patients with heart failure with preserved ejection fraction also suggest that despite lower oxygen uptake, respiratory rate, and heart rate during Tai Chi compared to aerobic exercise, individuals who completed 12 weeks of Tai Chi evidenced greater improvements in the 6-minute walk test [137]. Though preliminary in nature, these findings suggest that there may be unique value in adding mindfulness to physical activity.

Pathways for Physical Activity Engagement

MBIs may exert their effects through several of the cognitive, emotional, and physical pathways in our conceptual model (Fig. 9.1). Anxiety and depressive symptoms, positive affect, intrinsic motivation, self-efficacy, and physical function have all been identified as key determinants of, or barriers to, long-term physical activity engagement [138–140].

Anxiety and depressive symptoms consistently predict poor exercise and cardiopulmonary rehabilitation adherence [139]. Both physical activity and mindfulness training alone are known to decrease anxiety and depressive symptoms, and MBIs that combine these therapeutic components may offer unique advantages for producing downstream improvements in physical activity engagement. MBIs may also target sources of distress that are unique to individuals with pulmonary conditions. Fears related to dyspnea, pain, and arousal-related sensations (e.g., elevated heart rate and dizziness) are common and are associated with heightened anxiety and depressive symptoms and avoidance of physical activity [141]. Preliminary work suggests that trait mindfulness may be associated with lower fears related to arousal-related sensations in pulmonary conditions [39]. In addition, MBIs that specifically target fear of internal physical sensations, such as acceptance and commitment therapy, appear to be useful for improving physical activity levels over time [121].

Positive affect is an important determinant of physical activity engagement. Studies have demonstrated that positive affective responses *during* exercise predicted physical activity levels up to 12 months later [140]. In one experimental study, participants exercised at a moderate intensity on a treadmill with and without mindfulness instruction. Compared to nonmindful aerobic exercise, mindful exercise (i.e., attending to body sensations in a nonjudgmental way) was associated with higher levels of acute positive affect and exercise enjoyment [142].

Intrinsic motivation (e.g., exercising for enjoyment) is associated with better exercise-related outcomes compared to external motivators (e.g., exercising to avoid criticism from others) [143]. MBIs may inherently promote intrinsic forms of motivation. For example, observational studies suggest that higher levels of trait and state mindfulness and self-reported yoga practice are associated with higher levels of exercise motivation [118] and more internal reasons for exercise [144]. Similarly, exercise self-efficacy is a strong determinant of physical activity engagement [138, 145]. Results from studies in various populations, including severe chronic illness (e.g., chronic heart failure), show that Tai Chi and qigong programs may be effective for enhancing exercise-related self-efficacy [128].

Lastly, poor physical functioning represents a barrier to initiating and sustaining physical activity [146]. MBIs, particularly yoga and Tai Chi, are effective for improving several indices of physical function (e.g., strength and flexibility), including in pulmonary conditions. Given that yoga and Tai Chi typically involve low-to-moderate intensity exercise (i.e., based on oxygen consumption and maximum heart rate) [147–149], these therapies may be safe and effective helping deconditioned patients with moderate-to-severe pulmonary conditions to initiate and maintain physical activity. Over time, MBIs may improve physical and psychological functioning, foster self-efficacy and motivation for exercise, and allow patients to sustain exercise or successfully transition to other forms of physical activity.

Practical Considerations and Suggestions for Referring Pulmonary Patients to Mind–Body Interventions

Because MBIs are a diverse group of therapies, there may be certain interventions more suitable than others for a specific patient population. Simple considerations can be applied when recommending these interventions clinically. Table 9.2 provides a suggested framework for assessing pulmonary patients with respect to use or referral to MBIs. Disclosure rates to healthcare professionals of mind–body therapy or other integrative medicine use tend to be low. We suggest active inquiry on the part of healthcare professionals to gain a more comprehensive understanding of patients' needs and preferences [150, 151]. In the last decade, several frameworks have been developed to encourage history taking on the use of integrative and mind–body medicine and to assess patients according to a biopsychosocial approach [77, 152, 153].

For example, in a more deconditioned population, one might choose a gentler style of movement therapy, such as Yang style Tai Chi or a specific program geared toward older adults. In patients with depression, an approach like MBCT has been

Table 9.2 Mind–body assessment and practical considerations for referring the pulmonary patient to mind–body interventions

Domain	Assessment	Sample questions	Considerations
Mind–body practices	Assess previous use (reasons, perceived helpfulness, side effects) Assess openness to use	*What are your experiences using mind–body interventions?* *What do you think about trying practices like meditation, Tai Chi, or yoga?*	Depending on patient experience and preferences, can consider Reading materials, educational books Self-guided materials, mobile apps, home videos Group instruction in community classes, or longer retreats for more in-depth experience
Physical function	Evaluate physical activity levels and barriers Assess mobility/physical limitations Explore how pulmonary symptoms impact functional status	*What keeps you from doing your everyday activities?* *What type of physical activity would you be interested in doing? Do you have limitations?*	If currently inactive, can consider more active MBI such as Tai Chi or yoga to encourage physical activity If deconditioned, consider gentler styles or tailored classes (e.g., Yang style Tai Chi for older adults) If significant physical limitations, consider chair yoga or seated mindfulness meditation If patient is unable to travel from home, consider mind–body apps (e.g., Insight Timer, Calm, Headspace)
Psychological function	Assess how psychological function impacts pulmonary symptoms (e.g., dyspnea) and health behavior engagement (e.g., smoking cessation) Explore emotional health, mood, sources of stress	*Have your emotions or feelings made living with [pulmonary condition] difficult? Or maintaining healthy behaviors difficult?* *How does having [pulmonary condition] cause stress in your life?*	For mild psychosocial problems, consider group-based mindfulness, yoga, Tai Chi class For moderate–severe psychosocial problems, consider evidence-based mind–body therapies with mental healthcare professionals (e.g., Mindfulness-Based Cognitive Therapy) For targeting smoking cessation, consider evidence-based mind–body therapies that teach coping with cravings and negative affect (e.g., Mindfulness-Based Relapse Prevention)

(continued)

Table 9.2 (continued)

Domain	Assessment	Sample questions	Considerations
Social function and support	Evaluate context for patient's wellness (e.g., family support) Assess how social function impacts health behavior engagement	*Who do you rely on for support?* *Are there others who help you in engaging in healthy behaviors (exercise, stop smoking, take your medications,* etc.*)?*	If socially isolated, consider group-based classes in the community (e.g., Tai Chi) Consider engaging family members, partners in trying mind–body practices together with the patient
Spiritual and cultural	Assess religion or spirituality as sources of hope and meaning Explore potential cultural influences to healthcare engagement	*Do you have spiritual or cultural beliefs that help you cope with [pulmonary condition]?* *How do your beliefs influence how you take care of yourself or make decisions about your healthcare?*	Consider patient factors that may support or interfere with adoption of mind–body practices (e.g., exposure to or comfort with Eastern traditions) Consider that certain mind–body practices may have spiritual components Depending on religious beliefs, may refer to more explicitly secular practices (e.g., Mindfulness-Based Stress Reduction)

shown to be effective. In considering mind–body breathing exercises with COPD patients, one might focus on diaphragmatic breathing or exercises that emphasize complete exhalation and practice prolonging the expiratory phase. Healthcare professionals can counsel patients to tailor exercises as needed and speak with their instructors about modifications if there are musculoskeletal or cardiopulmonary endurance limitations. One qualitative study among COPD patients and healthcare professionals who care for COPD patients revealed acceptability of mindfulness approaches in COPD disease management, use in combination with pulmonary rehabilitation, and the benefit of booster sessions to maintain gains [49].

Pulmonary healthcare professionals can successfully help guide patients with pulmonary conditions on the use of MBIs. A myriad of options are available to patients who seek MBIs, including community classes, online resources, mobile applications, and private lessons. Increasingly, group classes are being offered through hospitals and academic centers that may be better informed by available scientific evidence and have instructors with particular expertise or experience working with patients with chronic illness [154]. Some mindfulness-based therapies are offered by clinical psychologists or social workers in counseling sessions, with standard referral procedures and insurance coverage. However, most classes, even those offered in medical settings, are not covered by insurance and are self-pay. Costs vary but tend to be similar to community-based exercise classes. Many programs adopt affordable pay structures, such as sliding scale payment. Low cost and accessible options are often available at local YMCAs, community centers, or schools.

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Chapter 10
Strategies to Improve Adherence to Supplemental Oxygen Therapy

Susan S. Jacobs and Chris Garvey

The Rationale for Using Oxygen: What We Know

Home oxygen therapy, sometimes referred to as domiciliary oxygen, has been prescribed for patients with lung disease since the early 1950's with the goals of relieving hypoxemia and dyspnea, increasing survival, and improving HRQoL. In the United States, an estimated 1.4 million Medicare beneficiaries use home oxygen with 82% having a diagnosis of chronic obstructive pulmonary disease (COPD) [1]. Globally, other professional societies and investigators have also identified the need for evidence-based guidance and education for the prescription and reimbursement of oxygen [2–4]. Home oxygen therapy is a uniquely complex treatment – not a medication to take every morning, but a combination of equipment, technology, physical ability, knowledge regarding titration of dosing, changes to the home environment, and challenges with mobility and travel. The definition of optimal oxygen therapy was addressed in an official American Thoracic Society workshop report (Fig. 10.1) [5]. This definition confirms that successful patient engagement with this multidimensional therapy requires early education, combined with effective communication between the patient, healthcare professional, and oxygen supplier. The evidence supporting the benefits of oxygen therapy on survival and HRQoL for patients with different types and severity of lung disease is scarce. However, despite the paucity of data, the provision of home oxygen remains a common treatment for patients with chronic lung disease. Oxygen therapy clearly incorporates the art – the

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> *"Optimal oxygen therapy prioritizes maximizing each individual patient's quality-of-life and health outcomes with a goal to minimize the burden on patients, their families, providers, payers, and oxygen suppliers.*
>
> *Key Principles:*
> - *Optimal oxygen therapy requires an effective and transparent interface between patients, caregivers, clinicians, DME companies and payers to ensure patient-centered, long-term management of hypoxemia.*
>
> - *A qualified clinician provides initial and ongoing assessment of hypoxemia, and establishment of an oxygen prescription during rest, exertion, and sleep (and high altitude if needed) and ensures an individualized action plan and therapeutic patient education program.*
>
> - *The collaborative efforts of the clinician and DME company provide patient-centered oxygen systems that are clinically effective, safe, and support maximal long term mobility, management of hypoxemia, and address comorbidities including frailty, cognitive and/or physical impairments, as well as patient financial constraints."*

Fig. 10.1 Definition of optimal home oxygen therapy. (Reprinted with permission of the American Thoracic Society. Copyright 2019 American Thoracic Society. Jacobs et al. [5])

communication and relationship with the patient and caregivers – and the science – the evidence for the benefits of oxygen, and the evidence on how to enhance adherence to this commonly prescribed therapy.

Survival Benefit of Oxygen Therapy

The scientific rationale for the prescription of oxygen is based on historic data of two studies completed in the early 1980's involving patients with chronic obstructive pulmonary disease (COPD) with severe daytime hypoxemia [6, 7]. Results confirmed a dose-dependent survival benefit for COPD patients with moderate-to-severe resting hypoxemia who used oxygen for at least 15 hours per day, compared to those who only used nocturnal oxygen. Subsequently, 35 years later, the 2016 Long-Term Oxygen Treatment Trial (LOTT) study found no difference in time to all-cause mortality, hospitalizations, HRQoL, or exercise performance in COPD patients with mild resting or moderate exertional hypoxemia who were randomized to use oxygen or no oxygen [8]. Other investigators have advised caution in extrapolating the LOTT results to patients with other lung diseases such as interstitial lung disease (ILD) [9], whose pattern of exertional oxygen desaturation is often more rapid and with a lower nadir, despite similar baseline oxygen saturations and other matched baseline variables [10].

There is no available evidence on the survival benefit of treating either resting or exertion-only hypoxemia in patients with other lung diseases such as ILD, pulmonary hypertension (PH), cystic fibrosis (CF), or rare cystic lung diseases such as lymphangioleiomyomatosis (LAM). Despite the lack of evidence for a survival benefit in other lung disease patients, current clinical practice extrapolates the COPD data to support the prescription of continuous supplemental oxygen for resting hypoxemia in patients with a variety of other lung diseases. Patients in the United States with exertion-only hypoxemia meet prescription requirements of the Centers for Medicaid and Medicare Services (CMS), despite lack of supporting evidence of long-term benefits. Outside of the United States, ambulatory oxygen may only be provided to patients with exertion-only hypoxemia who meet additional criteria such as an increase in 6-Minute Walk Test (6MWT) distance or decreased dyspnea when using oxygen compared with a blinded trial of medical air [2], or other formal assessments demonstrating improved exercise tolerance [11]. When educating those patients with resting hypoxemia on the rationale for their oxygen prescription, it is important to include the impact of prolonged hypoxemia on co-morbidities such as pulmonary hypertension and cardiac arrhythmias that can indirectly affect survival.

Improvements in Exercise Capacity, Physical Activity, and Mobility

As a component of prescribing oxygen therapy, healthcare professionals should support patients to understand that using ambulatory oxygen systems to correct their exertional hypoxemia *may* improve their exercise capacity or level of physical activity, and lessen their exertional breathlessness. Overall, the available evidence demonstrates the benefit of oxygen for improving exertional breathlessness and exercise capacity. However, study methodologies vary as to whether or not participants were blinded to portable oxygen use; whether testing was done in a laboratory setting, during 6MWTs, or during daily physical activity; if results were clinically significant; and the length of the intervention periods. Laboratory testing such as cycle ergometry more consistently confirms improvements in exercise capacity whereas 6MWTs, or daily activity monitors, such as step counters, may not.

One study of 76 ILD participants with exertion-only hypoxemia (≤88%) using a randomized, cross-over design compared outcomes for participants randomized to the use of a lightweight portable oxygen canister or to no oxygen for 2 weeks, and then crossed over for another 2 weeks [12]. The study found no difference in physical activity levels or step counts between the two groups, although participants reported improved HRQoL, decreased breathlessness, and the ability to "do more" when using ambulatory oxygen.

Meta analyses of 12 studies on the effect of oxygen therapy on ILD patients' breathlessness included 8 studies of patients using ambulatory oxygen only, and 4 using long-term oxygen and examined outcomes of HRQoL, exercise capacity, and survival. While the effect on end-exercise dyspnea was inconsistent across the 8 identified randomized, controlled trials (RCTs), the use of oxygen consistently improved exercise outcomes [13]. Other investigators found that, in a sample of mixed severe lung disease patients, carrying a sham cylinder of air at 4 L/min resulted in decreased exercise capacity and worse dyspnea. However, these negative effects were offset when using cylinders with oxygen at 2, 4, and 6 L/min;

improvements in 6MWT distance and dyspnea increased incrementally with each increase in oxygen liter flow setting [14]. The 2016 Cochrane review of ambulatory and short-burst oxygen therapy in ILD [15] was inconclusive and unable to recommend or refute the use of oxygen to improve exercise capacity, HRQoL, or exertional dyspnea based on the limited evidence with the review including only three qualifying studies. Other smaller, uncontrolled studies in ILD patients have confirmed a benefit in 6MWT distance and dyspnea when using oxygen compared to no oxygen [16, 17]. One trial is currently underway to examine the benefit of oxygen use in ILD patients experiencing hypoxemia only during exertion in order to fill this particular gap in available evidence (NCT 02551068, HOPE-IPF; High Oxygen Delivery to Preserve Exercise Capacity in IPF Patients Treated with Nintedanib).

The effect of ambulatory oxygen on exercise tolerance in COPD patients has been widely studied [18–21]. In a recent in-depth review of oxygen use in COPD patients [22], three randomized trials of ambulatory oxygen therapy in patients who qualified for continuous oxygen, found no improvements in physical activity or 6MWT distance [23–25]. This same review included three randomized trials evaluating the use of ambulatory oxygen with activity compared to compressed air in patients who only desaturate with activity. These three studies found no clinically significant improvements in step tests, five-minute walk test, 6MWT distance, or physical activity [26–28]. A diagnosis of depression, less social support, supplemental oxygen use, and season predict overall decreases in physical activity, in participants with COPD for whom physical activity was actively promoted [29].

Despite varied findings from RCTs examining the benefits of long-term or exertion-only oxygen use, patient-reported data indicate that many patients desire portable oxygen devices to increase their mobility. In one survey sample of patients with a mix of chronic lung diseases, 70% reported having an average of 2–4 hours of portable oxygen supply, but 66% wanted 5–6 hours of supply, indicating that portability was important to increase their ability to leave the house for longer periods of time [30]. In another sample of 417 COPD patients, perceived satisfaction with the portable oxygen device positively affected perceived mobility [31]. However, qualitative studies using thematic analysis of oxygen survey patient responses reveal common themes of decreased mobility, inability to "get out of the house," and inability to complete activities of daily living because of inadequate portable oxygen options [31–33]. "Because of the limits of my current oxygen, I am mostly homebound. The oxygen available to me is too heavy to carry or too bulky to wheel, so an outing is more trouble than it's worth" (patient response to oxygen survey) [33].

Improvements in Breathlessness and HRQoL

Breathlessness is a strong predictor of HRQoL for ILD and COPD patients; therefore, the prescription of home oxygen is a key element of non-pharmacologic symptom management, along with pulmonary rehabilitation, smoking cessation, social support, and palliative care. Oxygen therapy is physically heavy, cumbersome, and visibly imparts negative social and emotional implications. Prescribing such a therapy complicates the purpose of improving dyspnea and HRQoL by asking patients to carry, wear, monitor, and titrate their oxygen. The usual initial onset of supplemental oxygen use with exertion is significant for patients and their families; it is a visible confirmation of disease progression. The need for oxygen at rest is another key transition or “touchpoint” [34] affecting patients’ HRQoL and as such needs acknowledgment and support from clinicians.

The greatest hope for patients is that supplemental oxygen will decrease their dyspnea, especially with activity, and allow them to be more active. While RCTs do not consistently confirm an exercise or activity benefit from using ambulatory oxygen in patients with exertion-only hypoxemia, others have found improvements in HRQoL [35] and mood [36]. The AmbOx study confirmed improved HRQoL, walking ability, and breathlessness with the use of portable oxygen; 67% of the patients completing the study chose to continue using a portable oxygen device [12]. In-depth interviews with 20 of these participants reported benefits of less breathlessness, not having to stop as much when doing activities, reduced cough, fatigue, and dizziness, and the ability to “do more” [12].

Home oxygen users do report difficulties using their prescribed oxygen due to equipment problems, lack of physically manageable portable oxygen devices, inadequate amount of oxygen to leave the house, and lack of education and training concerning their oxygen equipment and use (Fig. 10.2) [30]. Content analysis was conducted on 745 open-ended responses from supplemental oxygen users to an oxygen survey question, “Is there some issue, other than those mentioned above, that you are having related to your oxygen?” Key themes included these patients’ constant worry and anxiety about running out of oxygen [33]. Family and other caregivers also feel the impact of knowing their lives are forever changed [37].

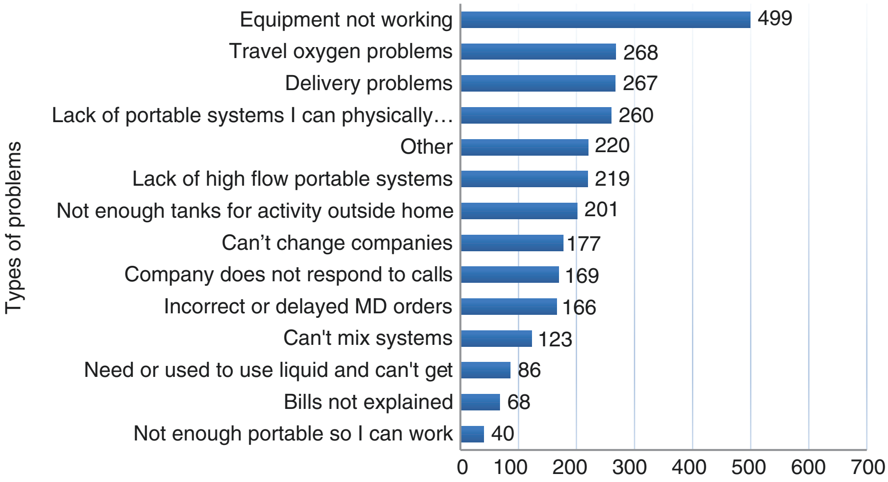

Fig. 10.2 Types of oxygen problems reported by patients. (Reprinted with permission of the American Thoracic Society. Copyright 2019 American Thoracic Society. Jacobs et al. [30])

Patients with hypoxemia share common symptom experiences concerning the use of supplemental oxygen. The symptom cluster of dyspnea, fatigue, and anxiety is frequent, even though the mechanisms for hypoxemia vary across lung diseases (Table 10.1). Characteristics that are particular to each population are important to consider when providing oxygen. COPD patients' disease progression is typically slower, and therefore their oxygen use may be over more years and with lower flow rates/oxygen needs. COPD patients' respiratory rates are slower due to airway obstruction and thus the triggering of pulse devices may be more reliable. The dyspnea of COPD patients correlates with dynamic hyperinflation, especially during exertion, and interventions such as pursed lip breathing may help. In contrast, ILD patients have restrictive physiology, stiffer and less compliant lungs, more rapid shallow breathing patterns, shorter survival times (particularly in idiopathic pulmonary fibrosis), and high-flow oxygen needs. ILD patients may not be able to use pulse–dose systems due to their breathing patterns as well as high-flow oxygen needs. ILD patients also may have more rapidly changing oxygen needs; equipment initially dispensed to them may not be sufficient 6 months later due to progression of their ILD, particularly in IPF patients. Patterns of desaturation are also different between COPD and ILD, with the latter having a more rapid and steep pattern of desaturation with exertion [10].

Younger patients needing oxygen have unique needs. Young women with lymphangioleiomyomatosis (LAM), a rare, cystic lung disease, are typically diagnosed during childbearing years. They may need high-flow oxygen, and are often working and caring for young children. Cystic fibrosis patients also fall into this younger group with different oxygen needs for mobility to work or attend school. The mechanisms of hypoxemia plus patient characteristics become important when addressing barriers to adherence to oxygen.

Summary Despite varied and sometimes scarce evidence supporting survival, exercise/activity, dyspnea, and HRQoL benefits, oxygen remains a common tool for symptom and disease management. For patients with resting hypoxemia, the survival benefit is clear and these patients need this information to understand the importance of adherence to long-term oxygen therapy. For patients with exertion-only hypoxemia, the data are lacking and patient response may vary; this is an opportunity for shared decision-making between the patient and clinician regarding weighing the potential benefits of less dyspnea and improved mobility vs the harm (safety, burdensome equipment) of ambulatory oxygen.

From the Healthcare Professionals' Perspective

Overview

Healthcare professionals are the critical link between patients and their Durable Medical Equipment (DME) oxygen supply company. Healthcare professionals prescribe home oxygen to improve survival, manage hypoxemia, improve dyspnea, and

Table 10.1 Characteristics of oxygen by pulmonary diagnosis

	COPD	Alpha 1	ILD	PH	CF	LAM
Predominant mechanisms of hypoxemia	Destruction of alveolar-capillary membrane Air-trapping and V/Q mismatch	Destruction of alveolar-capillary membrane due to antitrypsin deficiency. Air-trapping and V/Q mismatch	Thickening of alveolar-capillary membrane due to fibrotic and inflammatory changes V/Q mismatch Destruction of pulmonary vasculature	Destruction of alveolar-capillary membrane due to pulmonary vascular changes V/Q mismatch	Secretions, infection, airway inflammation	Multiple thin-walled cysts, airway obstruction
Clinical findings	Hyperinflation Prolonged expiratory phase Clubbing Accessory muscle use	Hyperinflation Prolonged expiratory phase Clubbing Accessory muscle use	Rapid, shallow breathing pattern especially with exertion +/− clubbing Cough – dry	Profound hypoxemia Clubbing	Hypoxemia with advanced disease Cough – productive	Hypoxemia with advanced disease
PFT findings	Airflow obstruction Decreased FEV_1, increased TLC, RV, FRC Decreased FEV_1/FVC ratio Decreased DLCO	Airflow obstruction Decreased FEV_1, increased TLC, RV, FRC Decreased FEV_1/FVC ratio Decreased DLCO	Decreased FVC, Decreased FEV1, decreased TLC, RV, FRC Increased FEV1/FVC ratio Decreased DLCO, usually in proportion to decrease in FVC	Decreased DLCO out of proportion to decrease in FEV_1 or FVC	Airway obstruction Decreased FEV_1, increased TLC, RV, FRC Decreased FEV_1/FVC ratio Decreased DLCO	Airway obstruction Decreased FEV1, increased TLC, RV, FRC Decreased FEV_1/FVC ratio Decreased DLCO

(continued)

Table 10.1 (continued)

	COPD	Alpha 1	ILD	PH	CF	LAM
Oxygen needs	Low flow Consideration of hypoxemic drive to breathe Lower target saturation levels	Low flow Consideration of hypoxemic drive to breathe Lower target saturation levels	High flow	High flow	Varies	Varies
Other considerations	Long-term use	Long-term use	Rapid progression and increase in oxygen needs can occur	Younger population	Younger population	Women only – typically during child-bearing years

COPD chronic obstructive lung disease, *ILD* interstitial lung disease, *PH* pulmonary hypertension, *CF* cystic fibrosis, *LAM* lymphangioleiomyomatosis, *V/Q* ventilation/perfusion, *FEV1* forced expiratory volume in 1 second, *TLC* total lung capacity, *RV* residual volume, *FRC* functional residual capacity, *DLCO* diffusion capacity of carbon monoxide ideally enhance physical activity and functional capacity. However, they frequently experience numerous challenges that prevent optimal oxygen prescription and provision that undermine patient engagement and adherence, and limit achievement of the goals of therapy. Both healthcare professionals and patients should understand the current framework of stationary and ambulatory oxygen insurance requirements, coverage, and availability, as well as common practices of DME companies and related challenges. Having tools to work with the limits of the current system is key, yet the insurance coverage requirements and the variations among DME suppliers often preclude the delivery of optimal oxygen therapy.

This section describes what is currently known, and provides a sample of available resources to inform both healthcare professionals and patients. Key elements of improving oxygen use and adherence include an informed, effective healthcare professional as well as patient communication, patient involvement and education, and use of appropriate patient and caregiver resources. Healthcare professionals should also be aware that prescribing oxygen under the current framework may be, at least indirectly, associated with restriction in independence and HRQoL [5, 30, 38]. An open, appropriately resourced interface with the patient and DME company may help engage the patient and caregiver to support decisions and problem-solving regarding ambulatory oxygen. It is also recognized that the availability and prescription guidelines of home stationary and portable oxygen systems vary by geographic region; for example, ambulatory oxygen for exertion-only hypoxemia may not be an option in some areas globally.

Rationale for Prescription An important aspect of prescribing oxygen is patient engagement including outlining causes of hypoxemia and potential consequences of inadequate management. Patients, families, and caregivers should receive specific information about the advantages and disadvantages of different types of oxygen systems (Table 10.2).

Patient education, communication, and resources may help patients understand DME company limitations, and how they can advocate for oxygen systems that do not “take their breath away.” Patients should understand processes for addressing concerns regarding inadequate equipment, supplies, instruction, and support. They need their DME company contact information as well as a Medicare or insurance contact for addressing concerns not resolved by their oxygen supplier.

Patient engagement is the cornerstone of behavior change, including oxygen adherence.

Strategies to facilitate patient acclimation to ongoing use of ambulatory oxygen include the following:

- Clinicians providing a device demonstration so that patients can see, learn about, and, when appropriate, try out oxygen systems, conserving devices, and supplies such as reservoir cannulas
- Patient referral to pulmonary rehabilitation for oxygen education, demonstration, demystification, Q & A, and support
- Clinicians offering an option for patients to try oxygen intermittently to acclimate to therapy as clinically appropriate

Table 10.2 Four common home oxygen systems[a]

System	Advantages	Disadvantages
Stationary oxygen concentrator	Continuous flow oxygen Ambulation (with caution to prevent falls) with 50-feet tubing Bleed in oxygen to non-invasive ventilation (if used)	Exclusively for stationary use Noise may be excessive 50-feet tubing may be a fall risk Cost of utilities for running concentrator[b]
Portable oxygen concentrator (POC)	Portable Approved for air travel Battery operated; can recharge	Smaller units appeal to patients but often deliver the lowest flow rate Limit to 3 L/min continuous flow No standardization of flow rates, e.g., setting of "2" has no relationship to "2 L/min", oxygen delivery varies between POCs on same pulse-dose setting Some POCs are 10–20 lbs Costly, often not covered by insurance Progressive or severe hypoxemia may exceed the limits of POCs
Gaseous oxygen: E-cylinders	May support high-flow oxygen needs Continuous oxygen delivery an option	Weight may jeopardize safety and mobility including stair climbing, transporting in and out of car, etc.
Gaseous oxygen: M 6 cylinders	Light weight – may be carried in a backpack or shoulder pack May be used with oxygen conserving device to extend duration in patients requiring lower flow rates	Short duration especially in patients requiring continuous and high-flow oxygen
Liquid oxygen: Stationary reservoir and portable canisters	Allows patient to fill lightweight canisters from home reservoir Supports high-flow needs 4–15 L/min continuous flow Allows storage of more oxygen in portable canister	Not available across all geographic regions Costly due to weekly delivery needs and specialized delivery trucks

[a] Equipment options and terminology vary globally

[b] Some utilities may provide discount for stationary concentrators

Requirements for Prescribing Oxygen

Oxygen prescription requirements are complex. CMS has specific patient supplemental oxygen eligibility criteria and strict requirements for the components to be included in the actual prescription (Table 10.3). At the time of the patient's encounter that confirms hypoxemia, all testing must be completed. After this "face-to-face" encounter, or patient visit, the treating healthcare professional completes a Written Order Prior to Delivery (WOPD). Documentation of the face-to-face examination and the WOPD must be in the DME's possession prior to delivery of oxygen equipment and supplies. It is important to note that the "face-to-face" encounter must be within 30 days of placing the order; if not, the patient will have to return for

Table 10.3 CMS oxygen eligibility criteria and prescription requirements

	CMS Requirements
Oxygen eligibility criteria	1. $PaO_2 \geq 55$ mm Hg or $SpO_2 > 88\%$, or PO_2 of 56–59 mm Hg or SpO_2 with either dependent edema suggesting CHF, PH or cor pulmonale, based on pulmonary artery pressure, gated blood pool scan, echocardiogram, or “P” pulmonale on EKG (P wave >3 mm in leads II, III, or AVF), or erythrocythemia with hematocrit >56%. 2. Severe lung disease such as COPD, IPF, cystic fibrosis, bronchiectasis, widespread pulmonary neoplasm, etc. 3. Qualification during inpatient stay requires the above assessment and documentation ≤2 days prior to discharge date, with O_2 beginning immediately following discharge. 4. Outpatient qualification requires a face-to-face encounter within 30 days of certification while the patient is in a chronic stable state as well as #1 and #2 above.
Written Order Prior to Delivery (WOPD)	1. The WOPD must include the following (a) Patient’s name. (b) Healthcare professional’s name. (c) Date of order (and start date if different). (d) Detailed description of the item(s). (e) Prescribing practitioner’s NPI number. (f) Ordering practitioner’s signature and signature date. (g) Items to be dispensed (oxygen system, e.g., tank, concentrator, etc.). (h) Dosage or concentration (flow rate). (i) Route, e.g., nasal cannula, etc. (j) Frequency of use, e.g., continuous, with exercise and activity, sleep, etc. (k) An employee of the healthcare professional may complete the WOPD; however, the healthcare professional must review, sign, and date it. 2. Medicare patient reassessment for oxygen need must occur every 12 months, although optimizing adherence and clinical effectiveness may clearly require more frequent reevaluation.

https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/Home-Oxygen-Therapy-Text-Only.pdf
CMS Centers for Medicare and Medicaid Services, *CHF* congestive heart failure, *COPD* chronic obstructive pulmonary disease, *IPF* Idiopathic Pulmonary Fibrosis

re-testing. Timely and ongoing reassessment of the continued need for oxygen, for example, following exacerbations or acute hospitalization, is also essential, as well as regular reassessment to document any increase in oxygen needs for patients.

Prescription for Rest, Exercise, Sleep

Prescription of oxygen systems should consider the patient’s functional capacity and activity goals, learning and language capabilities, home environment, oxygen dose, and safety needs. Key factors in appropriate oxygen prescription include assessment, prescribing appropriate equipment, and reassessment using the patient’s own equipment. Assessment requires accurate measurement of arterial oxygen saturation (SaO_2) (usually estimated by pulse oximetry, SpO_2) at rest, with activity, for example, walking and, when appropriate, during sleep. Assuring accurate measurement of SpO_2 may require use of forehead or earlobe oximeter sensor, especially in those with systemic sclerosis or Raynaud's syndrome. Prescription at rest should be performed after 20–30 minutes of rest. Prescription with exercise is performed using an oxygen system that will result in adequate SaO_2 or SpO_2 levels (normally 88% or above).

Prescribing nocturnal oxygen requires assessment and documentation of desaturation during sleep including $SpO_2 < 88\%$ for 5 minutes over a minimum of 2 hours of sleep (needs not be continuous). Testing may include nocturnal overnight oximetry (ONO) or polysomnogram (PSG) sleep study. Additional information is found at https://www.cms.gov/outreach-and-education/medicare-learning-network-mln/mlnproducts/downloads/home-oxygen-therapy-text-only.pdf

To support patient engagement, behavior change, and oxygen adherence, clinicians should solicit the patient's daily activity goals including return to work, school, hobbies, social activities, etc. at the time of oxygen initiation. Once these are determined, a collaborative discussion and plan regarding the role, potential use, and pros and cons of ambulatory oxygen should occur.

Selection of Oxygen Systems

Historically, the availability of various portable oxygen systems has varied. Prior to 2000, patients were relegated to large, cumbersome E-cylinders. Then portable liquid oxygen (LOX) systems became available, followed by portable oxygen concentrators (POCs). Since the competitive bidding process was instituted in the United States in 2011, there has been a dramatic reduction in many critical options for lightweight, portable, high-flow systems, including LOX, POCs, and trans-tracheal oxygen. Reduction in the provision of optimal systems, coupled with the decline in DME communication, customer service, and availability of DME respiratory care practitioners, has led to fewer oxygen options for healthcare professionals to prescribe. This has resulted in difficulties in providing oxygen systems capable of optimizing SpO_2, mobility, symptoms, HRQoL, and safety.

Healthcare professionals should understand the basics of matching appropriate equipment with the patient's physiologic, mobility, and safety needs in order to optimize short- and long-term adherence. Patients requiring $\geq$4 L/min continuous flow rate are typically candidates for either liquid oxygen (availability is currently severely limited in the United States and not available in all areas globally) or an E-cylinder (a large, heavy tank needing a trolley). The labeling system of metal gaseous oxygen cylinders also varies globally. Those patients who adequately maintain an $SpO_2 > 88\%$ on <4 L/min may be candidates for smaller tanks such as M6 or POCs. Options may be available for conserving oxygen to extend the duration of a portable oxygen system such as an oxygen conserving device (OCD) or a cannula with a reservoir (e.g., an Oxymizer ®). Note that reservoir cannulas require continuous oxygen and cannot be used with an OCD or pulse–dose oxygen often used with a POC. All prescribed systems require patient assessment at rest and with ambulation to determine optimal saturation, safety, and symptom control during the use of the specific device. Patients should be instructed to always bring their portable oxygen device to clinic visits with them so that they can be tested on their own device.

The advent of POCs offers the potential for smaller systems that do not require refills from a DME supplier, offer greater independence with travel, and less stigma associated with pulling a large green tank in public. Limitations of POCs are significant, and include lack of standardized pulse–dose, liter flow, or volume of oxygen based on numerical setting across the different POCs [39]. They are expensive (often $2,000–$3,000), often not paid for by insurance, lack the capacity to meet high-flow oxygen needs, do not adapt to a patient's potential for increase in oxygen needs, and have limited battery life.

Complex aspects of prescribing oxygen include patient need for high-flow and/or lightweight systems suited to promote clinical effectiveness, adherence, mobility, and safety. Challenges occur with the DME "one-size-fits-all" approach, for example, using E–cylinders as the standard portable system for patients regardless of functional, safety, or oxygen needs. Clinicians and patients both recognize that these large, heavy tanks are not designed to promote increased mobility, and may be unsafe and impractical for navigating stairs, uneven pavement, or for lifting in and out of cars. Patients also must wait for weekly or monthly deliveries of tanks, which adds stress due to unpredictable delivery schedules. Healthcare professionals may prescribe POCs for patients who work, have family responsibilities, or have goals of mobility, independence, and travel, yet these may not be a priority for the DME provider, and may be too costly for patients to purchase.

Patient Learning Needs at the Time of Prescription and DME Delivery

The oxygen prescription must include education for patient and caregiver on the benefits of supplemental oxygen (see Chap. 3), as well as how to safely use, including reducing risk of fire and burns by avoiding smoking, fires, flames, sparks, and oil-based products such as nasal petroleum jelly or ointment near oxygen systems. Caution regarding potential fall risk from long tubing and large tanks is required. Patient education regarding benefits of supplemental oxygen should include risks of untreated or undertreated hypoxia. Patients should understand that oxygen is not addicting and that its use confers benefits based on consistent use following a prescription as opposed to sporadic dosing. Use during activity including showering and bathing as well as exercise should be emphasized. Contact with water should be avoided for electrical oxygen systems including stationary or portable concentrators. Tanks and tubing should be dried off after showering or bathing.

Patient self-management, engagement, and optimization of treatment of hypoxemia may be improved with training using a model of “titrate to saturate,” or “titrate to migrate.” This model is likely best suited for patients with generally stable SpO_2 levels on oxygen and absence of significant hypercapnia, severe desaturation, significant PH, cardiovascular disease, cognitive decline, or significant psychiatric comorbidities. This requires patient understanding of proper use of both oxygen systems and oximetry, accurate SpO_2 readings and specific goals for SpO_2, and when and whom to ask for assistance. Training of a reliable, available caregiver and written instructions may further facilitate this model of care.

Patient and caregiver education regarding use of equipment appropriate for patients’ clinical, mobility, and safety needs is important, as well as resources for proper selection, DME supplier communication, and when and how to contact an ombudsman. Patients should have training on oxygen systems, operation, and expectations of their DME supplier (providing safe, appropriate oxygen equipment, sufficient training to support patient use, operations, and problem-solving, oxygen safety, when system and supplies will be delivered, and how to contact a DME company regarding equipment and/or billing concerns). For concerns regarding inadequate equipment, supplies, instruction, and support, patients need support and resources for understanding and using Medicare or insurance processes for addressing concerns not resolved by the DME supplier. Patient and professional societies offer written resources, information lines, and support groups that support treatment success and effective problem solving. Table 10.4 lists potential resources available to patients and families.

Communication Between the Patient and the Healthcare Professional

Patient assessment is required prior to prescribing oxygen, during titration, and at follow-up visits to assess effectiveness of current oxygen settings, adherence, barriers to use, understanding of oxygen prescription and rationale, and adequate provision of oxygen by the DME provider. Opportunities for improving effective patient utilization of oxygen include the following:

- Clarify office contact for patient questions and concerns.
- Reconcile oxygen prescription with patient at each visit including details of flow rate/settings and system for rest, exercise, and, if needed, for sleep. Instructions should be provided orally, in writing, and if available, with a link to video training.
- Educate patients in their native language and consider culturally responsive engagement in discussing the use of oxygen therapy.
- Review current DME provider, role, and problem solving for adequacy of systems and challenges, communication and patient resources for advocacy, and understanding of oxygen systems and proper use.

Table 10.4 Oxygen information resources for patients and healthcare professionals

1. Medicare
    (a) 1-800-MEDICARE for concerns about DME oxygen provision, services, and communication
    (b) "Your Medicare Coverage: Is my test, item, or service covered?" https://www.medicare.gov/coverage/oxygen-equipment-accessories
    (c) Where to get covered DME items by zip code https://www.medicare.gov/supplierdirectory/search.html
    (d) Durable Medical Equipment, Prosthetics, Orthotics, and Supplies Competitive Bidding Program: Temporary Gap (English and Spanish) Period https://www.medicare.gov/Pubs/pdf/12032-DMEPOS-Temporary-Gap-Period.pdf
    (e) Equipment coverage: https://www.medicare.gov/coverage/oxygen-equipment-accessories
2. Pulmonary Fibrosis Foundation: Oxygen Information Line and oxygen and travel brochures, webinar
    (a) Oxygen Therapy https://www.pulmonaryfibrosis.org/life-with-pf/oxygen-therapy– extensive patient and caregiver information about nearly every aspect of use of oxygen
    (b) Oxygen Information Line – 844-825-5733: Oxygen safety, types of oxygen systems, traveling with oxygen
3. American Lung Association: https://www.lung.org/lung-health-and-diseases/lung-procedures-and-tests/oxygen-therapy/ Phone line: 1-800-LUNGUSA (1-800-586-4872)
4. COPD Foundation: Oxygen line, website and resources: https://www.copdfoundation.org/Learn-More/I-am-a-Person-with-COPD/Oxygen.aspx
5. ATS Oxygen patient education statement: https://www.thoracic.org/patients/patient-resources/resources/oxygen-therapy.pdf
6. POCs: The Pulmonary Paper https://www.pulmonarypaper.org/
7. https://www.cms.gov/Outreach-and-Education/Medicare-Learning-Network-MLN/MLNProducts/Downloads/Home-Oxygen-Therapy-Text-Only.pdf
8. American Association for Respiratory care – resources for oxygen: http://www.aarc.org/resources/publications/adventures-oxyphile-2/
    (a) Respiratory Care Journal issue dedicated to the oxygen topic
    (b) Audio book of "Adventures of an Oxy-phile 2" by Thomas L. Petty MD
    (c) Supplemental Oxygen Information Brochure
    (d) A Guide to Portable Oxygen Concentrators

- Instruct patients to always bring their portable oxygen equipment to clinic visits.
- Re-test the patient including during ambulation, *using the patient's own system,* to confirm ongoing need for oxygen or to modify flow rate or use, for example, increase in oxygen flow rate for worsening of hypoxemia and/or progression of disease.
- Provide the patient with resources for optimizing oxygen selection, use, and self-management (Table 10.4).

Follow-up clinic visits provide the opportunity to continue the conversation between the healthcare professional and the patient and his/her family as to how they are doing with their home oxygen, and what questions and concerns have arisen. This is the "art" of engaging the patient. Table 10.5 lists common problems and suggested strategies to address each one.

Table 10.5 Managing common problems

Type of problem	Strategies
Prescription-related problems	
Delay in initial oxygen prescription OR Desired portable system not available (specific type of POC or LOX)	Healthcare Professional: Understand and follow insurance requirements for assessment, patient face-to-face evaluation, qualification criteria, documentation, and oxygen prescription. Provide effective, focused patient/caregiver education. Select and effectively communicate with DME supplier with demonstrated reliability of providing appropriate equipment, communication, and follow-up. Write letter of medical necessity to support request for particular system (e.g., LOX for high flow). Patient: Understand communication priorities: Contact DME supplier; if inadequate response, contact healthcare professional. If DME supplier persists with poor communication, inadequate or faulty oxygen equipment, supplies +/or support, contact insurance ombudsman to express concerns. Keep record of all communications. DME Supplier: Provide effective and timely assessment and communication with patient and healthcare professional, as well as clear information on available appropriate systems and alternatives and any patient costs.
Equipment/DME Supplier challenges	
Lack of education/training on delivered equipment	See resources in Table 10.4 for education on oxygen systems
Equipment malfunction	Advise DME supplier. If not addressed, contact healthcare professional. If unable to rectify, contact insurance ombudsman.
Not enough portable tanks to leave the home/work/travel for needed amount of time	Advise DME supplier. If not addressed, contact healthcare professional. If unable to rectify, contact insurance ombudsman.
Portable tanks do not deliver high enough liter flow/setting to maintain saturations >88%	Advise DME supplier. If not addressed, contact healthcare professional. If unable to rectify, contact insurance ombudsman.
Lack of available oxygen high-flow portable systems	Consider available alternatives, e.g., use of reservoir cannula (Oxymizer ®, etc.). Note that this must be used with continuous flow oxygen and requires ongoing patient assessment of SpO_2 for adequacy.
Removal or change of system used without healthcare professional order	Contact DME supplier. If not addressed, contact healthcare professional. If unable to rectify, contact insurance ombudsman.
Delayed/missed deliveries	Contact DME supplier. If not addressed, contact healthcare professional. If unable to rectify, contact insurance ombudsman.
Clinical challenges	
Epistaxis	Humidification of oxygen, regular patient use of saline nasal spray, non-petroleum nasal lubricants, use of simple mask as an alternative to nasal cannula.

Table 10.5 (continued)

Type of problem	Strategies
Patient no longer qualifies for oxygen	If clinically stable on room air at rest, exercise, and, if appropriate, during sleep, discontinue oxygen with plan for reassessment. If $SpO_2 < 88\%$ at rest, exercise or > 5 minutes during sleep (ONO or PSG), prescribe appropriate oxygen based on patient's documented requirements.

DME durable medical equipment, *LOX* liquid oxygen, *ONO* overnight oximetry, *PSG* polysomnography.

Improving Adherence to Oxygen Therapy

Despite oxygen currently being prescribed to over one million persons in the United States, and many more globally, existing data suggest that patient adherence is low, ranging from 40–75% [40–43]. Accurately monitoring adherence is difficult. The social, physical, logistical, and disease-related dimensions of oxygen therapy present multiple potential barriers to adherence. The conceptual model of the variables that affect the implementation of optimal oxygen therapy (Fig. 10.3) encapsulates multiple opportunities for engaging patients and their families with their oxygen therapy.

A recent secondary analysis conducted on 359 COPD participants assigned to the oxygen treatment group (either intermittent or continuous) in the LOTT trial confirmed the positive effect of early intervention on improving adherence [44]. At baseline, participants were asked to rate their perceived readiness, confidence, and the importance to use oxygen on a 0—10 scale (0 = not at all, 10 = very much). Measures of adherence were taken at baseline and during the first month, months 9–12, and month 13 to last follow-up. Self-reported adherence in hours/day of oxygen use was recorded in the short term (first month), medium term (9–12 months) and long term (13 months or more). High adherence was defined as ≥16 hours/day for prescribed continuous use or ≥8 hours/day for prescribed intermittent use (sleep and exertion only). Variables found to be significantly associated with long-term adherence were patient-centered factors of readiness, confidence, and importance to use oxygen at the time of initiation of oxygen therapy, and early high adherence in the first month [44]. High adherence in the medium term was associated with high adherence in the long term.

Other investigators confirmed this benefit of early intervention and education. In an online survey of 1,926 participants with a variety of lung diseases, respondents who received little or no initial education and training on their oxygen equipment were more likely to report "Yes" to having oxygen problems [30]. Patients who reported oxygen problems had a higher rate of having an emergency room or hospital admission in the previous year [30], highlighting the significance of early intervention. Other previously identified predictors of higher adherence to oxygen therapy include older age, use of ambulatory oxygen [41], education by a healthcare professional or physiotherapist, smoking cessation, not having side effects from the oxygen treatment [42], and formal assessment and training [43].

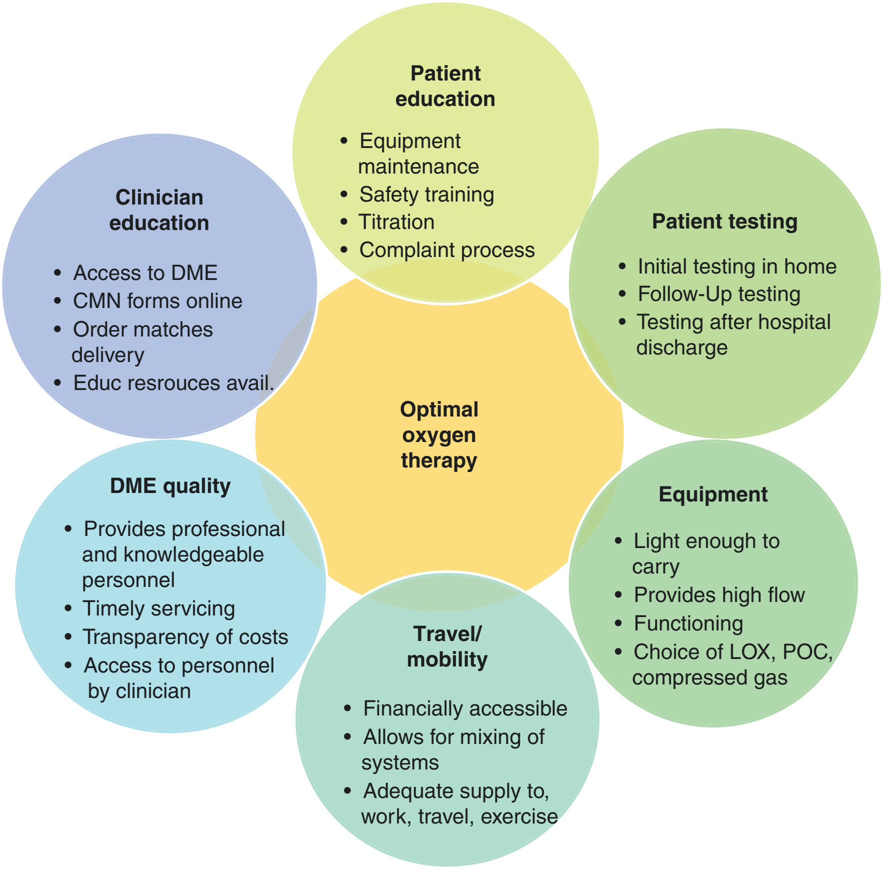

Fig. 10.3 Conceptual model of optimal oxygen therapy. (Reprinted with permission of the American Thoracic Society. Copyright 2019 American Thoracic Society. Jacobs et al. [5])

The onset of oxygen use is a key turning point for patients and families – a visual reminder of illness. A conversation with the patient and family needs to outline the expected benefits, as well as the possible negative impact that using supplemental oxygen devices bring. Patients may expect alleviation of their dyspnea and abandon the use of oxygen when they continue to experience breathlessness or the physical challenges are greater than expected. Even among healthcare professionals, perceptions of the benefits and the burdens of oxygen therapy vary [45]. This “mismatch” between expectations and reality when using supplemental oxygen is consistently described across different lung disease populations [46]. Patients described the positive impact of using oxygen to include feeling less tired, exhausted, and dizzy, and having less cough, decreased sensation of rapid or hard heartbeat, and feeling stronger, with the ability to be more mobile outside the house, with more security, and less stress and anxiety [46].

Unmet expectations included less than hoped for reduction in dyspnea, being self-conscious in public, worrying about running out of oxygen, being less mobile because of cumbersome equipment, and inability to travel [46]. Not receiving adequate guidance and support is also an important factor [47], with more frail and complex patients having lower adherence to long-term oxygen therapy [48].

A systematic review of literature including 42 studies on patient perceptions of oxygen therapy, and 9 on healthcare professionals' perceptions, revealed a theme of patients being uncertain about the purpose and benefits of supplemental oxygen, but following their healthcare professionals' advice nonetheless [49]. It is critical to address the rationale for the use of oxygen, self-management of oxygen with the use of a pulse oximeter, instructions on what their target oxygen saturation should be, and how to titrate oxygen based on activity. Barriers to adherence may also change over time when patients transition from exertion-only use to continuous use, and again when needing high-flow systems.

Summary and Conclusion

Engaging patients with their oxygen therapy combines the art of developing a relationship between the healthcare professional and the patient and family, with the science of implementing evidence-based treatment using known effective strategies. We know that adherence is low and that the treatment is burdensome – a combination that challenges healthcare professionals. Employing three strategies – mutual discussions with the patient and family, early oxygen education, and establishment of communication plans – can increase the likelihood of achieving important benefits from supplemental oxygen.

Key Strategies to Enhance Patient Engagement and Adherence to Supplemental Oxygen

- Include shared decision-making and managing expectations discussions at the time of initiating the oxygen prescription
- Provide early education and training on equipment, self-monitoring, titration, and problem solving
- Establish an effective communication plan between the patient, healthcare professional, and oxygen supplier

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Chapter 11
Self-Management: Personalized Action Plans for COPD Exacerbations

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Background

Chronic obstructive pulmonary disease (COPD) is characterized by progressive respiratory symptoms, increased functional impairment, and loss of HRQoL over the years [1–3]. Acute exacerbations of COPD contribute to functional impairment and risk of mortality in individuals with COPD [3, 4]. A COPD exacerbation is defined as a sustained worsening of the patient's condition from the stable state and beyond normal day-to-day variations that is acute in onset and necessitates a change in medication or hospitalization in a patient with underlying COPD, and can be associated with an increase in both respiratory (e.g., dyspnea and productive cough) and non-respiratory (e.g., fatigue and malaise) symptoms [5]. Aside from personal discomfort, COPD leads to a substantial and increasing economic and social burden on society [6], with acute exacerbations and associated hospitalizations accounting for most direct costs [7, 8].

Evidence suggests that self-management interventions, that often include action plans for COPD exacerbations, have positive effects on HRQoL, exacerbation duration, and hospitalization rates in patients with COPD [9–12]. A COPD self-management intervention has been defined as follows ([13], page 6):

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"Structured but personalized and often multi-component, with goals of motivating, engaging and supporting the patients to positively adapt their health behavior(s) and develop skills to better manage their disease.

The ultimate goals of self-management are: (a) optimizing and preserving physical health; (b) reducing symptoms and functional impairments in daily life and increasing emotional well-being, social well-being and quality of life; and (c) establishing effective alliances with healthcare professionals, family, friends and community.

*The process requires iterative interactions between patients and healthcare professionals who are competent in delivering self-management interventions. These patient-centered interactions focus on: (1) identifying needs, health beliefs and enhancing intrinsic motivations; (2) eliciting personalized goals; (3) formulating appropriate strategies (*e.g. *exacerbation management) to achieve these goals; and if required (4) evaluating and re-adjusting strategies. Behavior change techniques are used to elicit patient motivation, confidence and competence. Literacy sensitive approaches are used to enhance comprehensibility."*

Over the last 15 years, evidence around COPD self-management interventions has been accumulating. While only nine studies could be included in the first Cochrane review regarding self-management in patients with COPD published in 2003 [14], the latest update of this review published in 2014 included 23 studies [10]. Whereas no effects on respiratory hospitalizations and HRQoL were reported in the first review [14], the updates published in 2007 [15] and 2014 [10] both showed positive effects of self-management interventions on these outcomes. Similar positive effects were reported by an individual patient data review published in 2016 [11]. The body of evidence seems to confirm that COPD self-management interventions have positive effects on group level, but the effective components of the intervention are still unknown [9, 10, 16]. Nonetheless, a COPD exacerbation action plan is seen as an integral part of the COPD self-management intervention [9, 13, 17, 18].

Action planning is frequently applied as a planning technique in self-management interventions, and adopted to change behavior [19, 20]. COPD exacerbation action plans specifically promote self-management of exacerbations via the patient's early recognition of the development of an exacerbation [21]. COPD exacerbation action plans define the actions that patients should take if respiratory symptoms deteriorate; actions can vary from directing patients contacting a healthcare professional for support to starting self-treatment with oral corticosteroids (and antibiotics) [9]. Benefits of integration of COPD exacerbation action plans in COPD self-management interventions arise from earlier initiation of appropriate treatment resulting in less severe exacerbations, accelerated recovery, and reduced healthcare utilization [22, 23].

Many exacerbation action plans used in clinical practice are pre-defined by healthcare professionals but should ideally be tailored in collaboration with the patient (e.g., with regard to medications, comorbidities, and literacy level). We will discuss an example of a COPD exacerbation action plan that includes tailoring for comorbidities and has been evaluated in the COPE-III study later in this chapter [12, 24].

A Cochrane review published in 2017 assessed the effects of COPD self-management interventions that included COPD exacerbation action plans. The review reported that these interventions are associated with improvements in HRQoL, a lower probability of respiratory-related hospital admissions [9], and no excess in all-cause mortality risk (risk difference (RD) 0.00 (95% confidence interval (CI) −0.02 to 0.03)). Exploratory analysis of this Cochrane review showed however an unexpected finding, namely a small but significantly higher respiratory-related mortality rate for self-management compared to usual care (RD 0.04, 95% CI 0.01–0.07) [9]. This finding should be interpreted with caution because of the high risk of misclassification of the mortality cause [25], domination of the mortality effect by two studies [26, 27], and, most importantly, the robust analyses for all-cause mortality did not show any effect (nor trend) toward higher mortality due to self-management [9]. Moreover, two recently published studies evaluating multi-component case-manager-led programs showed significant lower mortality rates for the intervention group compared to the usual care group [18, 28]. The study of Kessler et al. [18] showed that compared to the usual care group, the disease management group had a lower mortality rate (1.9% versus 14.2%; $p < 0.001$). The one-year mortality rate in the usual care group of 14.2% is comparable to previously reported one-year mortality rates in COPD patients post hospitalization (between 12.5–21%) [29–31]. Compared to these rates, the mortality rate in the disease management group (1.9%) is much lower than expected [18]. One of the possible explanations provided by the authors for this finding was that the self-management of exacerbations could have been optimized, leading to early and prompt treatment, which could have prevented additional complications, including death [18]. The study of Rose et al. [28] intentionally included patients with COPD and at least two prognostically important COPD-associated comorbidities and also reported lower mortality rates in the intervention group compared to the usual care group (21 versus 36 deaths; hazard ratio (HR) 0.56, 95% CI 0.32–0.95). As in the study of Kessler et al. [18], training and support by case-managers was an important part of the intervention [28].

While there is a growing evidence for the effectiveness of exacerbation action plans integrated in COPD self-management interventions, there is no convincing evidence for using a sole COPD exacerbation action plan (i.e., not integrated in a COPD self-management intervention and/or no case-manager support). Whereas a meta-analysis on hospitalizations in the review of Howcroft et al. [23] regarding action plans with a brief patient education for exacerbations in COPD showed positive effects, this meta-analysis only included two studies, in which the study of Rice [32] had 92.3% of the weight toward the overall effects and dominated the analysis. As the intervention in this study [32] is classified as COPD self-management intervention including formal patient training program and case-management, this review provides no evidence for the use of sole action plans. Healthcare professionals should therefore be careful with just handing out COPD exacerbation action plans without involving a case-manager and patient training in the use of these action plans. Not only is the evidence regarding effectiveness missing, information regarding safety of the use of sole action plans is also lacking. Self-management interventions that include action plans should ideally contain specific training in the use of a COPD exacerbation action plan, including recognition of symptom deterioration, timing of personalized actions, and provision of feedback over time to improve self-management skills. Trained case-managers have an important role in coaching the patients and to reinforce the application of self-management skills [33].

In a recent review, the effectiveness of community-based self-management interventions among primary care COPD patients was evaluated [33]. In contrast to previous published reviews of COPD self-management interventions [9–11], this review did not report any positive (nor negative) effects of the intervention. The target population was clearly different from those explored in previous reviews, where most included studies had been conducted in secondary care with patients with more severe COPD. The primary care population is in general less severe, has a lower frequency of exacerbations, and may therefore have less room for improvement. Only four of the 12 included interventions in the primary care self-management review contained a COPD exacerbation action plan [33]. Whereas COPD exacerbation action plans are an integral part of COPD self-management interventions [9], they can only be effective in a population that exacerbates frequently. If this is not the case, there are no opportunities for patients to refer to their action plan and therefore learn from, or receive feedback on, their self-management actions [34]. The use of COPD exacerbation action plans and training in patients with a very low exacerbation frequency seems therefore less useful, and targeted applications with those who have a higher exacerbation rate may be a better allocation of resources.

There are several points to consider when introducing COPD exacerbation action plans to the treatment approaches of COPD patients. In addition to the importance of implementing action plans in conjunction with self-management interventions as discussed above, some other essential factors arise from the literature [9, 13, 17, 35–38]: (1) patient's adherence and the importance of tailoring self-management interventions to the needs, health beliefs, and readiness level of the patient [13]; (2) ongoing case-manager support; (3) modify interventions to appropriate literacy levels; and (4) taking comorbidities into account when developing COPD exacerbation action plans. In Text Box 1, we have provided a patient example case for clarification.

Patients' Adherence, Health Beliefs, and Readiness

Patients' adherence is of crucial interest for all treatment approaches, including self-management interventions, as effects on health outcomes can only be expected if patients are adherent to a treatment approach [39]. Patients' adherence is defined by the World Health Organization as the extent to which a person's behavior, taking medication, following a diet, or executing lifestyle changes correspond with agreed recommendations from a healthcare professional [40].

Patients are not always motivated or willing to follow medical advice, even when there appear to be obvious benefits [39]. Patients' adherence can be influenced by structural, disease-related, social, and psychological factors [41]. COPD is a challenging condition to self-manage and support as the patient's social, emotional, and

Text Box 1 Patient example case

Ben is 60 years old, lives with his wife and quit smoking 5 years ago (after having had a heart attack). He was working in road maintenance but had to retire early because of his health problems.

Ben has been diagnosed with severe COPD and is a frequent visitor of the respiratory outpatient clinic. He is always accompanied by his wife who takes an active role in the decision making. Ben has had two exacerbations that were treated with prednisolone and antibiotics in the last year, for one of these exacerbations he had to be hospitalized. After this hospitalization he completed a pulmonary rehabilitation intervention, he almost attended all the sessions and his 6-minute walking distance increased with 100 meters after he had completed the pulmonary rehabilitation intervention.

Besides severe COPD (FEV1% predicted: 40; modified MRC dyspnea score: 2), Ben has also been diagnosed with ischemic heart disease (IHD) and chronic heart failure (CHF). He is using a short-acting reliever and a combination agent containing inhaled corticosteroids along with long-acting beta agonists.

Consider the following issues in relation to the selection of an action plan and training:

1. **Are there any barriers for using a COPD exacerbation action plan?**
2. **Would you consider starting training in the use of an action plan?**
    - **If so, what action plan would/could you choose?**

Readiness

For behavior change to occur, patients need to feel that it will benefit them personally and that change is achievable. So the intervention and associated education need to be personalized. Before initiating a COPD exacerbation action plan training, it is advisable to assess the patient's current level of readiness using the stages of change model [48, 49]. If a patient is in the early stages of change (pre-contemplation or contemplation), action-oriented guidance is most likely less efficient. Personalized education with motivational interviewing is advised to facilitate patient readiness toward the "preparation" or "action" stages before starting the actual COPD exacerbation action plan training.

Ben

After the healthcare professional has discussed the pros and cons of using a COPD exacerbation action plan with Ben, he is very keen to start with the COPD exacerbation action plan. Ben states that he would like to start with it as soon as possible while being asked "Would you say you are not ready to change in the next 6 months, thinking about changing in the next 6 months, thinking about changing in the next month, or have you already made some progress?" He is therefore in the "Preparation stage" and ready to start with *the actual training in the use of the exacerbation action plan. The role of the healthcare professional is to motivate and encourage gradual goal setting while introducing the daily symptom diary and COPD exacerbation action plan. The training as outlined in Text Box 2 can be used for this.*

Exacerbation frequency

It is important to realize that if the patient's symptoms do not vary with some frequency and exacerbations are rare, there will be no opportunities for patients to refer to their action plan and therefore learn from or receive feedback on their actions. The use of COPD exacerbation action plans and training in patients with a very low exacerbation frequency seems therefore less useful.

Ben

Ben has had two exacerbations that were treated with prednisolone and antibiotics in the last year. As previous exacerbations are a strong predictor for future exacerbations, the introduction of an exacerbation action plan in Ben's treatment may therefore have benefits.

Health literacy

Before prescribing an action plan, the healthcare professional should try to get an idea of the level of the patient's health literacy. A single question is useful for detecting patients with inadequate health literacy: "How confident are you filling out medical forms by yourself?" More comprehensive multidimensional testing of health literacy (print and numeracy literacy, skill-based concepts) can be performed with a mixed-method approach (objective and subjective measurements) [106]. Pictorial COPD action plans or very simple "one-step" COPD exacerbation action plans may be an alternative for people with low literacy.

Ben

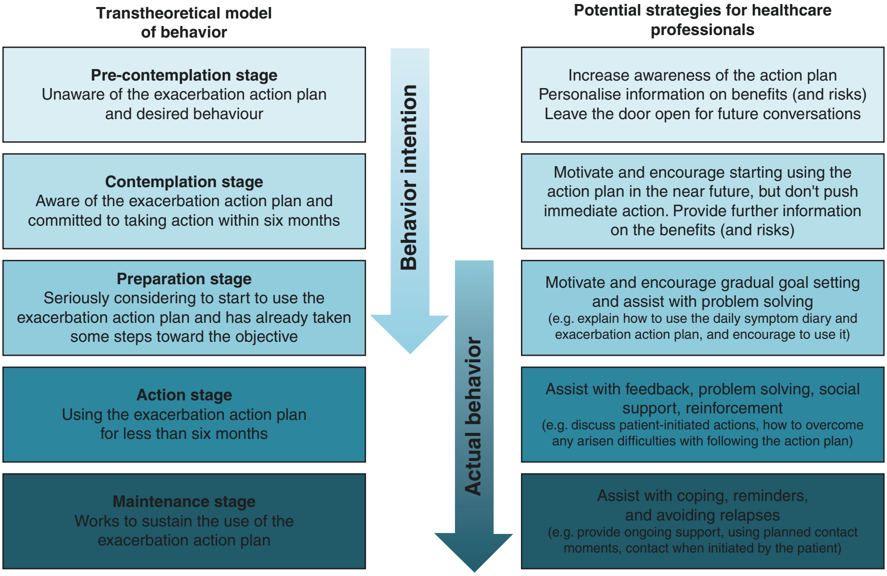
As Ben is always accompanied by his wife who is quite dominant during the consults with the healthcare professional, it is important to get an idea about Ben's health literacy level before introducing the exacerbation action plan training. Whereas the carers are encouraged to take part in COPD self-management interventions, the patient needs to be an active partner in the process. After having had a meeting with Ben alone, Ben's health literacy level is assessed and thought to be adequate for the COPD exacerbation action plan. So no tailoring of the exacerbation action plan for health literacy level is necessary.

Comorbidities

When serious comorbidities are present, the use of symptom-based COPD action plans in self-management interventions may be potentially limited and unsafe. Comorbid symptoms can overlap with COPD symptoms and this may lead to incorrect actions and delay in proper treatment. For safety reasons, it is therefore wise to take comorbidities such as IHD, CHF, anxiety, depression, and diabetes into account when using COPD-specific exacerbation action plans.

Ben

Ben is diagnosed with IHD and CHF and does not have diabetes. He is asked by the healthcare professional to complete the Hospital Anxiety and Depression Questionnaire [107] *to assess his depression and anxiety level. Whereas his anxiety score is low, his depression score is high. He is referred to a psychologist and the "anxiety and depression" component is also added to the action plan. Ben will therefore be trained in the use of a daily symptom diary and exacerbation action plan that is directed toward COPD, IHD, CHF and anxiety and depression* (Figs. 11.1, 11.2, and 11.3, Text Box 2). *As Ben has CHF, the dizziness component will also be added to his action plan because of safety reasons.*



Note: Content of Figure based on Prochaska 1992

Fig. 11.1 Stages of Transtheoretical model of behavior change and potential strategies for healthcare professionals

medical needs are varied and complex [41]. COPD patients are non-adherent to approximately half of their therapies, and this poor adherence is associated with increased mortality, exacerbations, hospitalizations, and diminished HRQoL, as well as increased economic burden [39, 42]. Individual barriers to COPD therapy adherence include the complexity and cost of regimens, incorrect medication knowledge and beliefs, cognitive decline that contributes to difficulties in performing activities of daily living [43], and inadequate health literacy [42]. Several patient characteristics have been reported to increase the likelihood of adherence to an action plan, that is, younger age, living with others, and having a cardiac comorbidity [27, 44].

Patients' beliefs around treatment and illness will drive their decision to act on a given health behavior. The Health Belief Model (HBM) is employed as an explanatory model to understand how individual patient-level factors influence health outcomes [45, 46]. It is understood that if the individual is able to perceive the risks associated with a given condition, he or she may be more likely to seek health-improving behaviors in order to prevent the condition or reduce its progression [45, 46]. It is therefore necessary to discuss both the negative effects of exacerbations on respiratory and non-respiratory symptoms and the positive effects of starting appropriate treatment in a timely manner (i.e., reduction in the severity of exacerbations and reduction in negative health outcomes such as hospitalizations). Presenting to patients how their current health outcomes relate to their reference group (e.g., by using graphs and trend data) may also help to show the urgency of treatment and motivate patients to adhere to treatment goals [47].

Before initiating the actual patient training regarding the COPD exacerbation action plan use, it is advisable to assess the patient's current level of readiness. This can be evaluated by employing questions based on the Transtheoretical Model (also called the Stages of Change Model) [48] (Fig. 11.1). This model hypothesizes that individuals move through stages of change: pre-contemplation (unaware of problem), contemplation (aware of problem and of the desired behavioral change), preparation (intends to take action), action (practices the desired behavior), and maintenance (works to sustain the behavioral change) [48]. In clinical practice, assessing the stage of change typically entails a straightforward question: "Would you say you are not ready to change in the next 6 months (pre-contemplation), thinking about changing in the next 6 months (contemplation), thinking about changing in the next month (preparation), or have you already made some progress (action)?" [49]. Norcross [49] states that the majority of patients are not in "action phase," as 40% are estimated to be in the pre-contemplation phase, 40% in the contemplation, and only 20% are actually prepared for action. If the healthcare professional assumes that the patient has greater readiness to change than there actually is, resistance and patient non-adherence will be likely [50]. If a patient is in the early stages of change (pre-contemplation or contemplation), action-oriented guidance is most likely less efficient and personalized education with motivational interviewing is advised to facilitate patient readiness toward the "preparation" or "action" stages before starting the actual COPD exacerbation action plan training. Figure 11.4 includes some strategies that healthcare professionals can use in the different stages of change with regard to the use of COPD exacerbation action plans.

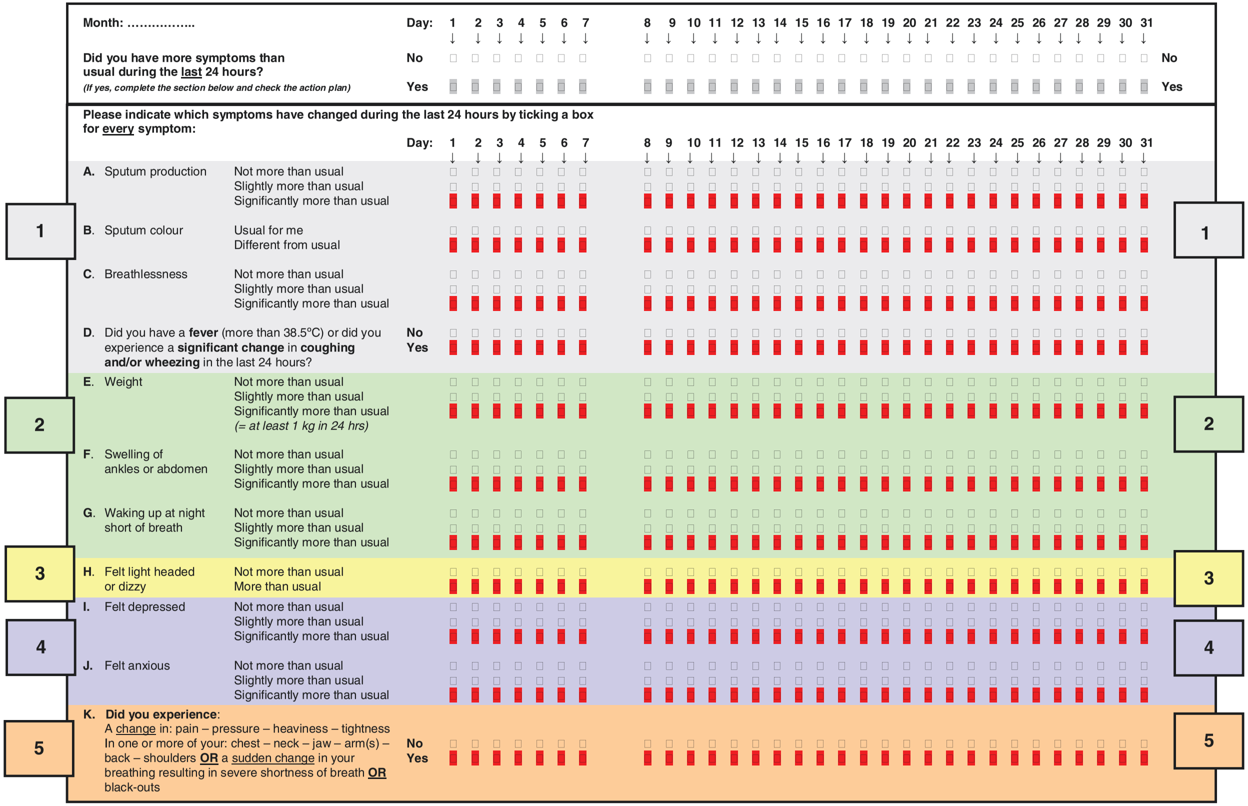
Patients' activation is defined as the individual's knowledge, skills, and confidence in managing their own health and care [36, 51] and influences the patient's role in decision-making and taking responsibility for maintaining their own health [36]. Patient activation is a more generalized concept than readiness to change, as the latter is per definition linked to specific designated behavior [52]. A frequently used instrument for measuring patients' level of activation is the Patient Activation Measure (PAM) [53–55]. The results of this instrument can not only be used to evaluate and compare the efficacy of interventions, but also support healthcare professionals to tailor their strategies to the level of activation of each patient [53]. We

Table 11.1 Tailoring COPD exacerbation action plan support to different activation levels as measured with the Patient Activation Measure [52]

Patient activation level	Potential strategies for healthcare professional
Patient is passive and feels overwhelmed by managing his/her own health	Focus on self-awareness and understanding behavior patterns of individual COPD patients and begin to build confidence through small steps What the healthcare professional might say to the patient: *"Let's not try to tackle everything right now. Let's focus on one thing, we can start with defining your usual symptoms."*
Patient lacks knowledge and confidence to manage his/her health	Help individual COPD patients to continue taking small steps, such as first using the daily symptom diary (Fig. 11.2) and then ask him/her to call you to discuss what to do if symptoms deteriorate (instead of following the exacerbation action plan and initiate self-treatment). Help them to build up their basic knowledge What the healthcare professional might say: *"You're off to a great start. Let's complete the diary for another month, and call me to discuss actions if your symptoms change …"*
Patient appears to take action, but is still not confident and skilled enough to support his/her behaviors	Work with individual COPD patients to adopt new behaviors and to develop some level of condition-specific knowledge and skills. Support the initiation of new "full" behaviors (those that are more than just small changes – e.g., initiate medication for an exacerbation according to the action plan) What the healthcare professional might say: *"You're making great advances. Do you think you're ready to start using the exacerbation action plan?"*
Patient has adopted many of the behaviors needed to support his/her health but may not be able to maintain it when under stress (e.g., when disease deteriorates)	Focus on preventing a COPD patient's relapse and handling new or challenging situations as they arise. Problem-solving and planning for difficult situations to help individual patients maintain their behaviors What the healthcare professional might say: *"You've had great success. Let's discuss how you can maintain that, especially when you are feeling quite unwell and have to start your exacerbation action plan."*

Note: This table is an adapted and merged version of Tables 1 (page 9) and 4 (page 23) in the paper of Hibbard 2014 [52]

have included some potential strategies for healthcare professionals, tailored to different patient activation levels, that can be used in patient training regarding exacerbation action plans (Table 11.1) [52]. Training in motivational interviewing and health coaching will support healthcare professionals to address the individual needs of patients at different levels of activation more effectively. Whereas patient activation has shown to play a central role in COPD self-management behaviors [56, 57], and is most likely interwoven with many used aspects in COPD self-management interventions, not many studies have specified the role of patient activation in COPD self-management interventions [56], and it remains unclear which intervention components will improve activation [54].



Month: ……………..

		1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31	
Did you have more symptoms than usual during the last 24 hours? ***(If yes, complete the section below and check the action plan)***	**No**	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	**No**
	Yes	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	▨	**Yes**

Please indicate which symptoms have changed during the last 24 hours by ticking a box for every symptom:

		Day:	1	2	3	4	5	6	7	8	9	10	11	12	13	14	15	16	17	18	19	20	21	22	23	24	25	26	27	28	29	30	31
1	**A.** Sputum production	Not more than usual	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
		Slightly more than usual	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
		Significantly more than usual	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥
	B. Sputum colour	Usual for me	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
		Different from usual	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥
	C. Breathlessness	Not more than usual	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
		Slightly more than usual	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
		Significantly more than usual	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥
	D. Did you have a **fever** (more than 38.5°C) or did you experience a **significant change** in **coughing and/or wheezing** in the last 24 hours?	**No**	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
		Yes	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥
2	**E.** Weight	Not more than usual	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
		Slightly more than usual	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
		Significantly more than usual *(= at least 1 kg in 24 hrs)*	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥
	F. Swelling of ankles or abdomen	Not more than usual	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
		Slightly more than usual	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
		Significantly more than usual	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥
	G. Waking up at night short of breath	Not more than usual	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
		Slightly more than usual	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
		Significantly more than usual	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥
3	**H.** Felt light headed or dizzy	Not more than usual	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
		More than usual	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥
4	**I.** Felt depressed	Not more than usual	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
		Slightly more than usual	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
		Significantly more than usual	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥
	J. Felt anxious	Not more than usual	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
		Slightly more than usual	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
		Significantly more than usual	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥
5	**K. Did you experience**: A change in: pain – pressure – heaviness – tightness In one or more of your: chest – neck – jaw – arm(s) – back – shoulders **OR** a sudden change in your breathing resulting in severe shortness of breath **OR** black-outs	**No**	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐	☐
		Yes	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥	🟥

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Fig. 11.2 Example of a COPE-III daily symptom diary for COPD and comorbid symptoms

The Role of a Case-Manager

The case-manager serves as the patient's companion within the complicated world of healthcare and as the patient's coach in gaining knowledge, skills, tools, and confidence to become more active in their own care [58]. Case-managers that are part of effective COPD self-management studies frequently have a nursing background and can work alone or in a team [9, 10]. Ideally, case-managers work in close collaboration with the physician and have easy access to other healthcare professionals and medical data [17]. A recent study that used unlicensed health workers to support patient self-management did not find any intervention effects [59], clearly demonstrating the need for qualified personnel to fill these roles.

Provision of self-management support requires healthcare professionals to change their clinical behavior from medical experts to coaches [60]. A recent process evaluation concluded that changing practicing healthcare professional's role in shared decision-making is very complex and requires paying attention to skills and attitudes, as well as to contextual factors [61]. Whereas sufficient time and training is very likely a requirement for this role transition, a review toward the effectiveness of professional education on asthma self-management support had to conclude that due to the complex multi-component nature of initiatives and the diverse contexts in which they were delivered, it was not possible to define what would make an effective education intervention for healthcare professionals [60]. Effective initiatives were however more often guideline based, involved more frequently local opinion leaders and inter-professional education, and addressed particular theoretical framework domains such as social influences, environmental context and resources, behavioral regulation, beliefs about consequences, social/professional role and identity [60]. In addition, it may be worthwhile to focus on organizational learning to increase an organization's capacity to change work routines in a collaborative process [61]. Furthermore, it seems to be important to engage healthcare professionals in the implementation of self-management interventions and therefore offer them some dialog between other users (e.g., patients, case-managers, and healthcare professionals) and developers so that the intervention will also meet professionals' requirements [62].

Healthcare professionals need to move through similar steps as patients in their learning process that ideally should include the following: (1) a self-appraisal of knowledge and skills for teaching; (2) development of personal learning objectives; (3) completion of training targeted at meeting those learning objectives; and (4) assessment of competency for teaching [63]. For healthcare professionals to provide COPD self-management interventions including exacerbation action plans, a course in behavioral change techniques as, for example, motivational interviewing, is highly recommended as a minimum education.

Health Literacy

Besides health beliefs, patients' readiness, and activation, health literacy has been demonstrated to influence self-management behaviors [36, 64]. Health literacy, defined as personal characteristics and social resources needed for individuals and communities to access, understand, appraise, and use information and services in health decision-making [65], is a barrier for the use of COPD exacerbation action plans. The fact that only a third of patients with limited health literacy are able to comply with simple written instruction such as "Take two tablets by mouth twice daily" [66] illustrates that COPD exacerbation action plans are not suitable for all patients with COPD. A lack of health literacy skills leads to difficulties comprehending medical information [67], less understanding of (self-)treatment regimens, sub-optimal adherence, and lower self-management skills [68].

Although information regarding health literacy in COPD patients is limited [37], those with COPD may be especially at risk given that lower health literacy is more prevalent among the older population [37]. Aging and COPD are both associated with cognitive decline [43] and contribute as an individual barrier to COPD therapy adherence and to difficulties when using health information and healthcare services. Moreover, limited health literacy, when coupled with physical disabilities of COPD common in the elderly, hampers patients' participation in healthcare [69]. COPD and limited health literacy are both associated with a lower socio-economic status and a lower educational background [70, 71]. All these characteristics are associated with lower motivation for seeking information, and increased disease burden, healthcare utilization, and costs [72]. Limited health literacy also negatively influences patients' self-efficacy and self-care behaviors, which directly affects individual decisions, actions, and lifestyle behaviors, and plays a key role in the prevention and management of COPD [36, 73, 74]. COPD exacerbation action plans should therefore consider health literacy and be modular to allow patients to use self-management actions according to their personal needs and capabilities. Adaptations to the COPD action plans could be made both on content (e.g., tailored feedback and reminders on action plans use) and delivery modality (e.g., written text, pictorial aids, videotape, and verbal instructions) to address the impact of literacy on health. For example, a written text reminder to perform a self-treatment action "Dear patient, you were advised to take an action because of symptom deterioration in breathlessness. Did you already do this? You can find the action(s) (…)." could be adjusted for different levels of health literacy. The actions for self-treatment could, for example, be simplified into several steps in which the first step is to contact a healthcare professional for support. At a later stage, the self-treatment of symptoms could then be added. However, the health literacy levels of some patients will only allow a single-step action plan. Furthermore, the delivery modality of the reminder on the action could be changed into a verbal reminder with pictorial aids from the action that needs to be taken, and with links to the self-management information related to the action.

The complexity of the patient's environment (i.e., how information is provided and communicated, how care is organized) raise low literacy issues and will be an extra obstacle for patients who already have difficulties finding, understanding, and applying information to make informed healthcare decisions [75]. Healthcare organizations should therefore pay more attention to factors contributing to the accessibility, comprehensibility, and usefulness of health information and healthcare services for patients with limited health literacy [75]. Healthcare professionals should be aware of their communication to patients with limited health literacy as these patients are likely not asking for clarification because of feelings of shame and embarrassment [37]. For example, healthcare professionals could provide patient education on self-management (e.g., what are the triggers for exacerbations, how to recognize symptoms, and what to do when symptoms deteriorate) without medical jargon to enhance participation of patients in their own care and to enable patients to correctly self-administer medications, maintain positive health behaviors, and encourage a timely response to COPD exacerbations [37].

Due to an aging population and a growing number of patients with COPD, new approaches are used to support and manage care for these patients. COPD self-management interventions and action plans are increasingly provided using electronic health (e-health) technology at home to support patients in health communication (e.g., teleconsultation), self-monitoring (e.g., wearables), and self-treatment (e.g., telemedicine). These e-health interventions have made information easily accessible, and they have the potential to facilitate home-based self-management support to COPD patients by helping them to early detect COPD exacerbations, with more timely treatment, reduction in hospitalizations, and improved HRQoL [76]. Furthermore, they may be able to facilitate assisting patients with physical limitations and those who need frequent evaluation of their health status [76]. They also have the potential to foster greater patient engagement and less costly interventions [77]. Although more research into the effectiveness of these e-health interventions is still needed, at this point in time the science behind e-health in COPD is underdeveloped [78].

Optimizing patient's health literacy skills for the use of COPD exacerbation action plans is fundamental to improve patient's usability and adherence, and it would stimulate patients' self-care and engagement [62]. It is therefore essential to identify barriers to, and facilitators of, health literacy in self-management in COPD patients (e.g., digital literacy as an adoption barrier by lower sense of technological self-efficacy, a barrier to patients' ability to interpret and act upon device readings in a beneficial manner [79]) to optimally tailor COPD exacerbation action plans to health literacy levels, and intervene on individual factors to improve the adherence to exacerbation action plans. Moreover, COPD patients participating in self-management interventions and using a COPD exacerbation action plan face behavior change and learning demands. Participation in self-management interventions, for example, requires patients' understanding, the ability to identify an exacerbation, and to act appropriately upon deterioration of symptoms. Screening patients for conditions that will impede the learning process, such as cognitive and (e-)health literacy issues, is therefore an area needing development in COPD education to achieve effective self-management, successful behavior change, and improvement in health [63]. Before prescribing an action plan, the healthcare professional should try to get an idea of the level of the patient's health literacy. A single question may already be useful for detecting patients with inadequate health literacy: "How confident are you filling out medical forms by yourself ?" [66]. Pictorial aids in COPD action plans [80] or simplified "one-step" COPD exacerbation action plans (e.g., by asking patients to contact a healthcare professional for support only) may be an alternative for people with low literacy. Before patient-tailored COPD self-management can be effectively implemented and used at home, it is important to involve patients in investigating their individual needs and requirements regarding the use of health technology in COPD self-management. Hence, understanding the fit between everyday routines and health applications to support COPD self-management interventions is essential for a successful uptake and use [62].

Comorbidities

Most patients with COPD have comorbidities that may worsen health outcomes and add to the complexity of COPD care. The comorbidities can play a significant role in exacerbation triggers, motivation, and self-management behavior. Comorbidities, such as cardiac diseases, mental health issues, and diabetes, are present in the majority of COPD patients [81]. They share common risk factors (e.g., smoking, aging, and inactivity) and pathophysiology with COPD. Both COPD and tobacco smoking lead for example, to increased pulmonary and systemic inflammation, which contributes to the development of cardiovascular disease and other chronic diseases [82]. The increasing prevalence of comorbid conditions in COPD, mainly driven by an aging population, represents a major challenge to healthcare systems because they have an important impact on disease severity, hospital admission rates, survival, and costs [83, 84]. For example, anxiety and depression have been increasingly identified in patients with a high frequency of exacerbations, and are associated with noncompliance with medical treatment and increased healthcare utilization [85–87]. Patient-tailored action plans that take comorbidities into account are therefore especially important in COPD patients with multiple chronic conditions.

Overlap in symptoms, for example, breathlessness in patients with COPD and heart failure, could relate to either a COPD exacerbation or a sudden deterioration of cardiovascular disease, for example, heart failure or arrhythmia [88]. This can easily lead to delay in appropriate treatment as it complicates differentiation of both diseases [89], and may lead to a further increase in patient burden and healthcare costs by increased risks of exacerbations, hospitalizations, and mortality [81, 84]. COPD-specific action plan self-management strategies are unlikely to be effective when the trigger of the exacerbation is an underlying comorbidity [21]. In COPD patients with coexistent depression, it is suggested that up to two-thirds may not receive appropriate treatment for their depression [90, 91]. COPD exacerbations may also introduce a deterioration of comorbid conditions (e.g., prednisolone treatment of COPD exacerbations increases blood glucose levels, especially in patients with pre-existing diabetes). Personalized treatment, not only addressing COPD but also existing comorbidities, should therefore be the norm [92]. The provision of an exacerbation action plan that includes actions for COPD and comorbid exacerbations, as outlined in Fig. 11.3, is in line with this.

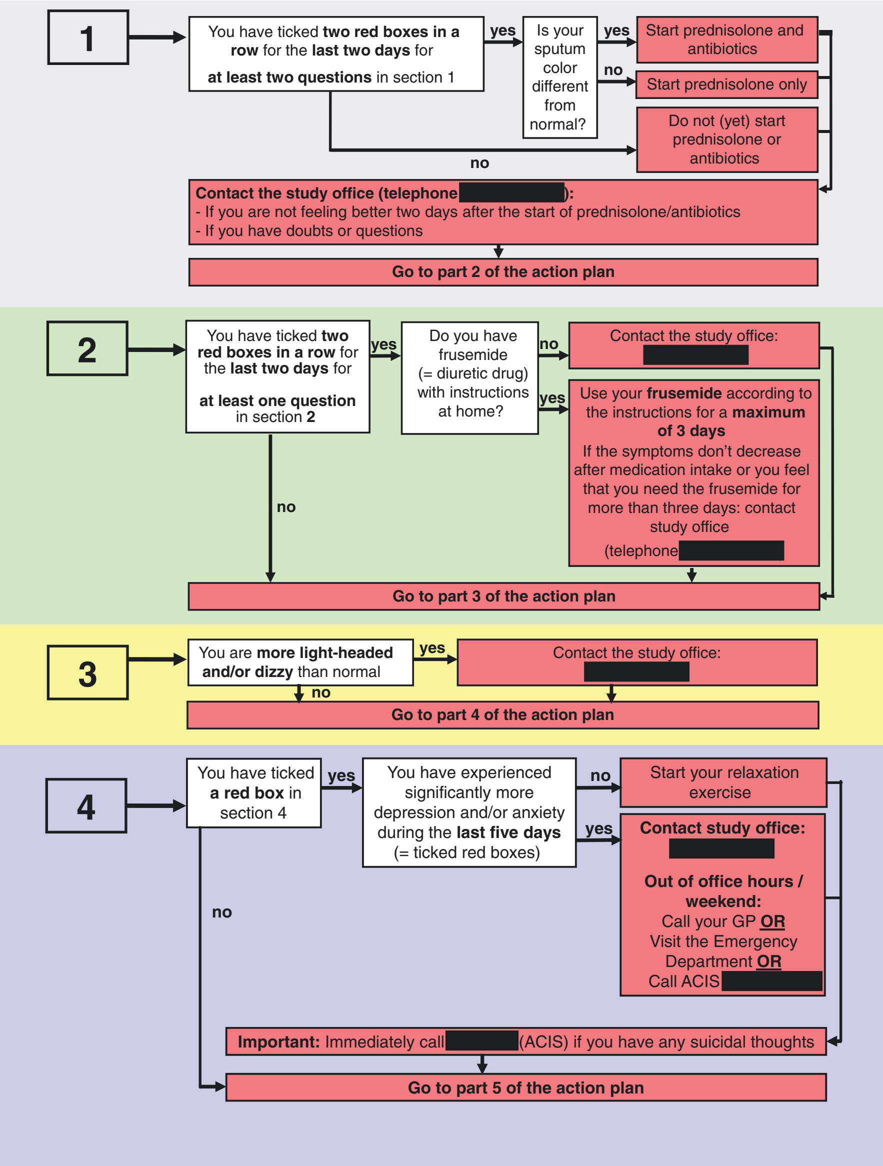
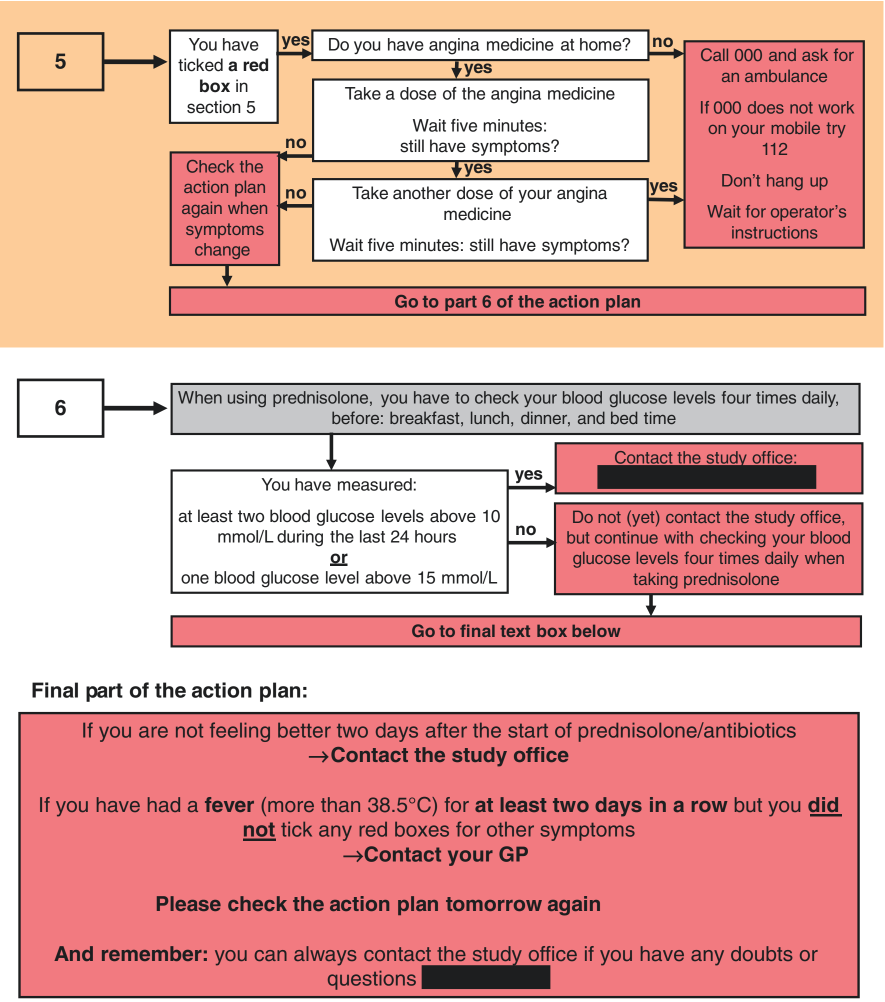


Fig. 11.3 Example of a COPE-III patient-tailored action plan for COPD and comorbid symptoms



Final part of the action plan:

If you are not feeling better two days after the start of prednisolone/antibiotics
→**Contact the study office**

If you have had a **fever** (more than 38.5°C) for **at least two days in a row** but you **did not** tick any red boxes for other symptoms
→**Contact your GP**

Please check the action plan tomorrow again

And remember: you can always contact the study office if you have any doubts or questions [redacted]

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Fig. 11.3 (continued)

Comorbidities also play a central negative role in the activation and management of self-management behaviors. These self-management behaviors refer to activities that individuals initiate and perform on their own behalf in the interest of maintaining and continuing health and well-being [56]. In the presence of comorbidities, it is more difficult for COPD patients to adopt and maintain new behaviors, and to become fully competent managers of their own health. For example, COPD patients who are depressed are less likely to gain activation and improvement in their self-management behaviors [56]. Patients may have difficulties going through the different levels of patient activation (Table 11.1) as they have to gain knowledge on multiple conditions and treatment options, and may lack confidence and the skills needed to support new behaviors that also address comorbidities (e.g., diet restrictions for COPD patients with comorbid heart failure, using prednisolone treatment for COPD exacerbations, and dealing with increased blood glucose levels in COPD patients with comorbid diabetes). Tailored approaches with patient-centered care and action plans are therefore required to promote positive lifestyle changes and self-management toward agreed goals to reduce treatment burden and optimize care for patients with COPD and comorbidities [92, 93].

The impact of comorbidities on HRQoL and mortality in COPD patients can be substantial [94] and therefore needs to be carefully considered when developing action plans and treatment strategies for patients [95]. Self-management interventions and self-treatment action plans are however frequently not adjusted for these comorbidities [9, 91]. Adjustments for comorbidities should focus on (1) providing patients with information regarding comorbid symptoms (e.g., discuss overlap in risks and symptoms between COPD, heart failure, and anxiety); (2) stimulating patients' mastery of self-management skills (e.g., discuss how to recognize flare-ups or exacerbations in COPD and comorbidities); and (3) providing personalized self-management actions directed to comorbidities in COPD to enable timely and appropriate treatment of comorbid symptoms, and to help patients put their knowledge and skills into practice in daily life [56] (e.g., discuss when to contact a healthcare professional for support or when to use diuretics or relaxation exercises, how to check and regulate blood glucose levels).

Clinical decision-making is complicated by the lack of adequate recommendations regarding the management of COPD patients, who may also suffer from other chronic conditions [96]. Efforts to improve the care for patients with chronic diseases have mainly focused on developing guidelines to implement standardized care for each disease [93, 97] and do not usually address comorbidities in their recommendations [81, 98]. Using disease-specific symptom-based COPD exacerbation action plans in self-management interventions may however be potentially limited, and actually unsafe. As said before, comorbid symptoms can overlap with COPD symptoms and this may lead to the initiation of incorrect actions and delay in appropriate treatment [88, 99]. For safety reasons, it is therefore wise that COPD self-management action plans take into account treatment for comorbidities such as ischemic heart disease, heart failure, anxiety, depression, and diabetes. An example of such an exacerbation action plan intervention is provided in Text Box 2; Fig. 11.3 [12, 34]. The importance of safety when using COPD self-management interventions including action plans has been highlighted by a study evaluating the efficacy of a comprehensive care management program in reducing the COPD hospitalization risk with COPD-specific action plans [26]. Premature termination of this study was enforced by the Data and Safety Monitoring board due to excess mortality in the intervention group. This higher mortality rate may be partly explained by the use of COPD-specific action plans in COPD patients with comorbidities. Considering comorbidities in action plans may not only increase the safety of COPD self-management interventions by appropriate and timely treatment actions, but will likely also increase its benefits.

COPD patients are often prescribed multiple treatments for their COPD and comorbidities, which may lead to complex pharmacotherapy regimens, a key contributor to non-adherence [100, 101], poor disease control, medication errors and

Text Box 2 Practical example: COPE-III self-management intervention [12]

The role of the case-manager can be best explained by using an existing COPD self-management intervention. We have chosen to use the "COPE-III self-management intervention" [12, 24]. The details of the COPE-III training, delivered by the case-manager, are listed below.

The self-management training provided by case-managers, in which carers are welcome to participate, consists of two 1-hour individual sessions, two 2-hour group sessions (4–8 patients), and three scheduled follow-up phone calls to check and consolidate behaviors. The training is specifically aimed to improve and reinforce the following self-management skills: problem-solving, decision-making, action planning, and self-tailoring. The behavior change components of education, training, modeling and enablement embedded in the self-management sessions target desirable and specific behaviors including individualized diary use, patient recognition of deterioration in symptoms, and the correct and timely use of an action plan.

The exacerbation action plan (Fig. 11.3) used by the patient is linked to a color-coded daily symptom diary including symptoms of COPD and comorbidities diagnosed at baseline (Fig. 11.2). At inclusion, all patients define, supported by the case-manager, their individual symptom levels in a stable health state on a 'What are my "usual" symptoms' card (Fig. 11.4). They are asked to compare their symptoms in the last 24 hours to their "usual" symptoms. In case of a significant change in any of the symptoms, patients are directed to the action plans and asked to follow the instructions as listed in their linked action plan (Fig. 11.3).

During the self-management sessions, the case-manger uses "self-management scenarios" to train the patient in completing the diaries and using the action plans. In addition, the patients will receive feedback from the case-manager on their "real-life" diary's completion and action plan use. The intervention has been designed in such a way that feedback to the patients on their behavior, to improve their skills and confidence, is frequently provided by the case-manager.

Week 1: Group session

- Knowledge regarding COPD and comorbidities: facts and figures to discuss positive effects of starting appropriate and timely treatment, and negative effects of exacerbations on health outcomes
- Symptom recognition and monitoring: triggers and overlap of symptoms
- Self-treatment of symptoms: action plan (Fig. 11.3) linked to diary (Fig. 11.2), discuss possible treatment options (e.g., lifestyle and medication)
- Breathing and relaxation exercises
- Patients with diabetes: extra session on how to check and regulate blood glucose levels when necessary

Week 2: Individual session

- Complete 'What are my "usual" symptoms' card (Fig. 11.4)
- Diary training: use patient scenarios to discuss how to monitor symptoms
- Exacerbation action plan training: use patient scenarios to discuss how to act upon symptom deterioration
- Mastery of skills (re-iterated when necessary), for example, correct inhaler techniques, early recognition of exacerbations, self-initiating correct and proper actions

Week 3: Group session

- Importance of physical fitness and exercise
- Diet and lifestyle behaviors
- Re-iteration of diary and action plan use
- Re-iteration of breathing and relaxation exercises

Week 4: Individual session

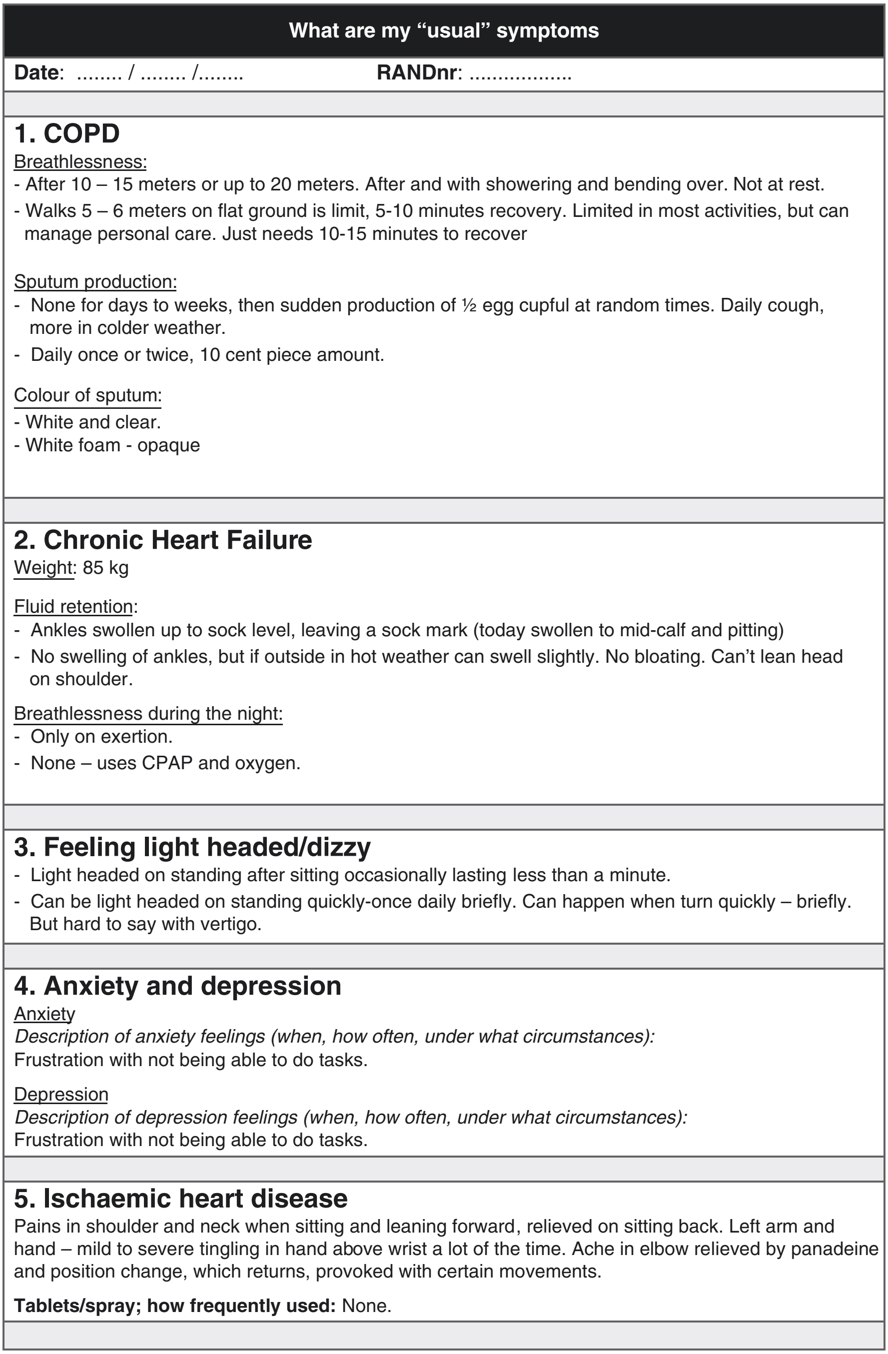
- Re-iteration diary and action plan use
- Feedback on diary completion
- Feedback on actions

Weeks 8, 20, and 36: Follow-up phone calls

- Feedback on diary and action plan use
- If necessary, adjust symptom levels on the "What are my 'usual' symptoms card"
- Check and consolidate behaviors
- Reinforce self-management skills

adverse drug events [102, 103], and substantial cost [104]. Therefore, a multidisciplinary treatment strategy should be considered for comorbid COPD patients as a collaborative effort could improve health outcomes in these patients [95]. The management of comorbid COPD could be improved by engaging a multidisciplinary team-based approach [95], in which healthcare specialists in COPD need to work together with professionals specialized in the management of other chronic diseases [81]. It is important that healthcare professionals provide extensive assessments and follow-up of comorbidities in COPD and are aware of the possibility of providing multi-disease self-management action plans to patients.

The importance of incorporating comorbidities in the assessment and management of COPD is gradually being recognized [91, 98], and multidimensional assessment and personalized disease management approaches aimed at addressing comorbidities have been suggested [105]. For example, the implementation of a chronic care model for optimal management of COPD has been proposed in clinical information systems, which support decision-making, use of evidence-based



What are my "usual" symptoms

Date: .... / .... /........ **RANDnr**: ....

1. COPD

Breathlessness:

- After 10 – 15 meters or up to 20 meters. After and with showering and bending over. Not at rest.
- Walks 5 – 6 meters on flat ground is limit, 5-10 minutes recovery. Limited in most activities, but can manage personal care. Just needs 10-15 minutes to recover

Sputum production:

- None for days to weeks, then sudden production of ½ egg cupful at random times. Daily cough, more in colder weather.
- Daily once or twice, 10 cent piece amount.

Colour of sputum:

- White and clear.
- White foam - opaque

2. Chronic Heart Failure

Weight: 85 kg

Fluid retention:

- Ankles swollen up to sock level, leaving a sock mark (today swollen to mid-calf and pitting)
- No swelling of ankles, but if outside in hot weather can swell slightly. No bloating. Can't lean head on shoulder.

Breathlessness during the night:

- Only on exertion.
- None – uses CPAP and oxygen.

3. Feeling light headed/dizzy

- Light headed on standing after sitting occasionally lasting less than a minute.
- Can be light headed on standing quickly-once daily briefly. Can happen when turn quickly – briefly. But hard to say with vertigo.

4. Anxiety and depression

Anxiety

Description of anxiety feelings (when, how often, under what circumstances):

Frustration with not being able to do tasks.

Depression

Description of depression feelings (when, how often, under what circumstances):

Frustration with not being able to do tasks.

5. Ischaemic heart disease

Pains in shoulder and neck when sitting and leaning forward, relieved on sitting back. Left arm and hand – mild to severe tingling in hand above wrist a lot of the time. Ache in elbow relieved by panadeine and position change, which returns, provoked with certain movements.

Tablets/spray; how frequently used: None.

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Fig. 11.4 Example of a COPE-III completed "What are my 'usual' symptoms" card guidelines, self-management education, and routine screening for common comorbid conditions in COPD [91]. Nevertheless, more work is still needed to better inform healthcare professionals and researchers on how to optimize the assessment and management of COPD in the presence of comorbidities.

Conclusion

COPD exacerbation action plans are considered as an integral part of a COPD self-management intervention with benefits arising from earlier initiation of appropriate treatment, decreasing the severity of exacerbations, accelerating recovery, and reducing healthcare utilization. There is no evidence for the effects of using a sole COPD exacerbation action plan, but a growing evidence for the effectiveness of action plans integrated in COPD self-management interventions.

In this chapter, we have discussed the fact that potential barriers for the use of action plans (e.g., current level of readiness, health literacy, and existing comorbidities) should be considered and taken into account in COPD exacerbation action plans and training.

We have provided the summary points of this chapter as key take-home messages in Text Box 3.

Text Box 3 Summary points as take-home message

- Always provide patient training when distributing COPD exacerbation action plans, as there is no evidence for positive effects of these action plans without patient training.
- Assess the patient’s current level of readiness before introducing the COPD exacerbation action plan to the patient.
- Assess the patient’s potential barriers for the use of COPD exacerbation action plans such as readiness, health literacy, and comorbidities. COPD exacerbation action plans should be tailored accordingly.

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Chapter 12
Domiciliary Noninvasive Ventilation: Strategies for Improving Adherence to Home Use

Nicolino Ambrosino

Introduction

Home mechanical ventilation is increasingly used in patients with chronic respiratory failure due to advanced diseases such as chronic obstructive pulmonary disease (COPD), restrictive thoracic disease, and neuromuscular disease (NMD) [1–4]. Home noninvasive ventilation (NIV) may reduce symptoms, improve HRQoL and exercise capacity, and, in many cases, reduce hospitalization and mortality rates [5–8]. Clinicians are well aware of the long-term benefits of home NIV, but they may underestimate the potential human and financial burden of the technological dependency for both patients and caregivers leading to reduced adherence. An analysis of public and private healthcare utilization and costs for NIV in Canada found that median healthcare monthly costs were $3,925, the highest costs being associated with diagnosis of amyotrophic lateral sclerosis and higher levels of dependency [9].

Low Versus High Adherence

Adherence to home NIV decreases the hospitalization rate with an improvement in prognosis when NIV adherence was >5 hours/day, whereas noncompliance leads to complications such as increased hospitalization rate [10, 11]. Therefore, knowledge of reasons for low or lack of adherence is crucial.

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Machine Settings Setting and timing of NIV has been found to influence adherence. In 2014, Borel and colleagues [12] found that spontaneous time mode and night use were more frequent, and inspiratory positive airway pressure values were significantly higher in high-adherence patients (night or daytime use more than 5 hours) than in low-adherence patients with COPD who had been using NIV for at least 1 year. However, there were no differences in hospitalization, emergency department and intensive care unit admission rates, or dyspnea or health status, whereas conjunctivitis was observed more frequently in the high-compliance group [12], suggesting that adherence does not necessarily significantly impact on health status.

Intelligent volume-assured pressure support (iVAPS) is a hybrid mode of servoventilation, providing constant automatic adjustment of pressure support ventilation (PSV) to achieve a target ventilation according to the patient's ventilatory requirements. iVAPS was as effective as PSV initiated by a skilled healthcare professional in controlling nocturnal hypoventilation and produced better overnight adherence in patients naive to NIV [13]. However, a recent meta-analysis shows that there is no significant difference in clinical outcomes and compliance when comparing iVAPS support and PSV [14]. Noninvasive ventilation settings determined during wakefulness may produce patient-ventilator asynchrony during sleep, causing sleep disruption and limiting tolerance. A study found that NIV titrated with polysomnography was associated with less patient-ventilator asynchronies but not less sleep disruption or better adherence when compared to therapy titrated during daytime alone [15]. The use of the nasal mask was associated with better adherence as compared to the use of the oronasal mask [16].

Demographics and Anthropometrics Patients with obstructive sleep apnea (OSA) under continuous positive airway pressure (CPAP) with poor adherence (use of device <4.5 hours per night) after 1 year of treatment were significantly younger, had higher body mass index (BMI), and required more unscheduled visits during the first year. After 12 months, dropouts were observed only among patients with poor adherence and were significantly more frequent during the first 5 years [16].

Other Factors Dry mouth, mask incompatibility, and gastrointestinal complaints have also been found to negatively influence adherence [12]. A study evaluated the compliance with NIV in patients with myotonic dystrophy type 1 and identified predictors of cessation at 5 years [17]. Compliance during the first year was higher when symptoms of respiratory failure were initially present and lower in the case of acute respiratory failure. Long-term compliance was associated with symptoms of respiratory failure and nocturnal arterial oxygen desaturation. Cessation was more frequent in the cases of excessive leaks, ventilator dysfunction requiring emergency technical intervention, or high BMI. Cessation was less frequent for patients with a professional occupation or undergoing professional training [17].

Table 12.1 Key factors for discharge plans to home with NIV

Decision-making	Appropriate information of patient and caregiver
Feasibility	Appropriate location
Education and training	Self-care
Needs	Balance between needs and resources
Follow-up	Role of stakeholders
Risk management	Minimization

Discharging Patients on Home NIV

Risks for reduced or lack of adherence to NIV programs may be avoided or decreased by the early use of discharge plans, when the appropriate setting of ventilation has been prescribed, together with the beginning of educational sessions [18]. A comprehensible and simple plan should include needs, wishes, and activities of all persons and institutions involved, such as patients, caregivers, and other stakeholders. This requires the collaboration among patients and their family members, professional caregivers, prescribing centers, provider companies, third-party payers, and other stakeholders, avoiding discrepancies between prescribing centers and the management in the home setting [19–22]. Table 12.1 shows the key elements in discharge planning [23].

A survey has shown that formal teaching of relevant knowledge and skills within the hospital setting prior to discharge had an immediate and long-lasting positive impact [24]. However, conflicts between families and professionals, information gaps, and persistent lack of trained caregivers at home were problems. Participants strongly recommended improved transitional care such as telephone support from respiratory health professionals, home outreach, in addition to training of caregivers [24].

Education

Education programs for patients and caregivers should be well structured, goal directed, and competence based with clear learning outcomes, aimed to the specific needs of individual patients and caregivers, respecting their willingness and autonomy. Theoretical and practical sessions are required (see Chap. 3). The specific knowledge and skills should be verified periodically in order to ensure that the caregiver (and the patient, when able) has acquired and still maintains the necessary abilities. Refreshment sessions should be provided when needed, dealing with equipment, potential problems and possible solutions, technical aspects such as ventilator type and setting, interfaces (different masks), day/nighttime of ventilatory support, and caregivers (professional vs relatives).

Table 12.2 Basic theoretical knowledge required by patients and caregivers

Anatomy and physiology of the airways
Working principles of the specific patient's ventilator
Appropriate humidification when applicable
Choice of masks: the importance of minimizing leaks and of transparency of material
Side effects
Risks of accidental disconnection from the ventilator

Table 12.3 Practical skills required by patients and caregivers to manage domiciliary NIV [26]

Positioning of the mask, selection of headgear and the proper tightening to prevent or minimize leaks, and pressure on the face
Airway clearance techniques
Recognition of signs of infections
Hygienic precautions when dealing with the ventilator, masks, circuits, humidifiers, and disposables
Understanding ventilator settings and troubleshooting, alarms, and related action
Assemble and disassemble relevant equipment, such as masks, the ventilator circuit, and the humidifier
Whom to call, and what to do, in an emergency
Resuscitation skills are sometimes included

Attention should be paid also to the workload and working conditions of caregivers, especially family members, including mental and emotional stress. Indeed, most caregivers of chronically critically ill patients report high levels of depressive symptoms, persisting up to 1 year and not decreasing in some caregivers [25]. Tables 12.2 and 12.3 show the minimal theoretical knowledge and the practical skills required by patients and caregivers [26]. However, currently organized training in NIV even for professionals is implemented only in a few developed countries [27].

Safety

Mechanical malfunctions of ventilators are rare in home NIV; however, mistakes in interaction between the user/caregiver and the ventilator may lead to problems, and therefore, risk management is an important aspect of home ventilation strategies. Monitoring is crucial for effectiveness of, and adherence to, ventilation, prevention of potential adverse effects, improvement of patient/caregiver training, maintenance of equipment, and resetting of ventilator settings according to the changing conditions of the patient [28].

Periodic clinical assessment is very useful, looking for improvements in nocturnal hypoventilation symptoms, sleep quality, and side effects, major cause of lack of adherence. Screening side effects may lead to the need to change the interface, gas humidification, or ventilator settings. Home care providers should maintain ventilator and interface, and also educate patients for correct use. Assessment of arterial blood gases may show significant improvement of hypercapnia when NIV is efficient or reveal worsening when application has not yet been optimized. Analysis of ventilator data may reveal daily use, unintentional leaks, upper airway obstruction, or patient-ventilator synchronies. Nocturnal oximetry and capnography are additional monitoring tools to assess the impact of NIV on gas exchanges [28]. Table 12.4 shows some common issues to monitor or periodically check.

Quality control of the equipment is necessary in order to ensure that patients safely and accurately receive the prescribed and required ventilatory support. An early survey [29] covering 16 European countries providing home mechanical ventilation to more than 20,000 patients showed with relevant inter- and intracountry differences that:

- The ventilator service was mainly carried out by external companies, with a frequency ranging 3–12 months.
- The interaction between companies and prescribers was limited.
- The participation of centers in equipment quality control was poor.

Patients under home NIV have a substantial requirement for assistance, but most technical problems can be resolved simply. Where no fault in equipment can be found during a check, the patient himself may have mistaken clinical deterioration for an equipment problem and should receive early clinical evaluation. This was shown by a report on the nature of calls to a home support helpline for more than 1,000 adult and pediatric patients on home ventilation [30]. There were more than 500 daytime and 10 nighttime calls per month. Home visits identified technical problems potentially fixable in 64% or required replacement or new parts of devices in 22% of cases. Rather interestingly, out of calls without any identified mechanical fault, half of patients were either found to be unwell or even required hospital admission [30].

Table 12.4 Common issues to monitor or periodically check

Clinical status
Mask condition
Ventilator setting
Arterial blood gases
Unintentional leaks
Patient-ventilator synchrony
Night pulse oximetry
Capnography

Tele-monitoring

The situation may be far more challenging if the patient lives in a regional location, a substantial distance from expert health centers. This may explain the growing interest in the development of tele-monitoring systems [31–35].

Starting and monitoring long-term NIV in an outpatient setting has been shown to be safe and feasible although without any clinical advantage as compared to usual care [36]. However, the use of tele-monitoring to adapt patients to home ventilation showed a reduction in healthcare resources consumption with clinical results and levels of adherence similar to in-hospital settings [37]. A randomized controlled trial of tele-assistance program for patients with chronic respiratory failure including COPD resulted in reduction in hospital admissions, general practitioner calls, and costs [35]. In a retrospective study, a tele-assistance program alone reduced the exacerbations rate of patients on long-term oxygen therapy, with greater effectiveness, when added to long-term NIV [38].

Information and communication technologies applied to healthcare and advances in sensor and data transmission technology allow tele-medicine-based programs. New sensors, transmission devices, and interventions have been developed to allow technology to support home care in new ways [31, 33, 39]. Ventilator data downloads, via early remote assessment, can help optimize patient ventilation through identification of modifiable factors, in particular, interface leak and ventilator prescriptions [40].

However, the acceptance of these systems by patients is not guaranteed. A recent survey on home ventilator users' perception of care provision across Europe [41] reported that only about half of respondent patients would be confident with a tele-monitoring system of their program. Unfortunately, another international survey on patterns of home NIV use in COPD patients reported that tele-medicine was only an option for 5% of respondents [42].

Practical Recommendations

On the basis of historical experience, several practical recommendations on NIV have been proposed, which may serve as an indication to proper use [20, 21, 43].

- Home NIV must be prescribed and organized in an experienced and authorized center, and the treating healthcare professional should be responsible for the organization of home care.
- Adaptation to NIV in the ambulatory setting is not inferior to hospital adaptation in terms of therapeutic equivalence in stable patients with chronic respiratory failure [15, 44, 45].
- The targets of program must be defined and clearly explained to the patient.

- Costs and supply of equipment, resources, and materials must be defined before discharge. Patients and caregivers must be instructed and must demonstrate that they know how to perform home NIV.
- In COPD patients with chronic hypercapnia, NIV is effective in improving arterial blood gases and in unloading inspiratory muscles independent of whether it is set on the basis of patient comfort and improvement in arterial blood gases or tailored to patients' respiratory muscle effort and mechanics [46].
- Appropriate application of expiratory positive airway pressure (EPAP) can abolish end-expiratory flow limitation and alleviate the intrinsic positive end-expiratory pressure, to reduce work of breathing and inspiratory triggering asynchronies [47].
- Auto-titrating modes of NIV providing variable support during changes in respiratory loads through sleep stages and disease progression may lead to enhanced clinical outcomes [48].
- Preliminary studies indicate that pressure–volume NIV combined with auto-titration of EPAP might be effective in reducing upper airway obstruction and in maintaining clinical stability in patients with COPD–OSA overlap, improving sleep comfort and compliance. Such modes of ventilation could be utilized to facilitate an outpatient setup [49].
- Changes to the ventilator or ventilator settings should always be performed under clinical conditions, with arterial blood gases and expert assessment of the patient [19]. Identically built machines with the same settings can be exchanged outside the hospital, whereas different machines must be exchanged under hospital conditions in the center for NIV [50].
- A humidifier, mandatory for invasive ventilation, may be also useful for NIV if typical symptoms are present [51].
- A number of masks each year must be agreed with the healthcare professional at the time of prescription. Each patient requires at least one reserve mask.
- Patients with NMD and weak or insufficient cough and children should be provided with a pulse oximeter and cough-supporting machines.
- The first follow-up visit must occur in the short term (4–8 weeks), and therapeutic success should be evaluated according to predefined subjective, clinical, and technically measurable parameters.
- The equipment provider must guarantee round-the-clock availability and ensure a prompt and customized service (including back-up and "switch out" ventilators, processes for rapid admission, etc.).
- Nutrition is a common problem in patients with chronic respiratory failure; therefore, it is a key component in the long-term management. As home ventilation is usually prescribed in end-stage respiratory disease patients with poor nutritional status, nutrition and dietary intake-related problems need to be carefully assessed and corrected [52].
- Patient-centered outcomes are significantly modified by home NIV, and we need short, self-administered, specific tool for routine clinical assessment [53].

Conclusion

The aim of home NIV is to sustain breathing and when possible a self-managed life in patients with severe chronic respiratory failure. The responsibilities of patients, caregivers, and health care professionals should be defined.

Key Messages

- Discharge planning is an evolving process according to changes in circumstances.
- Be proactive and identify in advance unique needs of patients and caregivers.
- Training of caregivers should be well structured, goal directed, and competence based.
- Teamwork and coordination of multiple stakeholders are the core issue of discharge to home noninvasive ventilation.
- An individualized package of care should be designed, with the agreement of the patient and caregivers, and this must be appropriate to their local situation.

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Chapter 13
Teaching the Practical Skill of Correct Inhaler Use: Knowing and Being Able to Do

Garner Faulkner II and Christopher J. Moore

Introduction

Patients with pulmonary disease (such as COPD and asthma) are often prescribed inhaled medications, since this is the most effective route for specific delivery to the lungs and airways [1–6]. Medication via the inhalation route allows for direct delivery, with faster response times (helping to alleviate symptoms/exacerbations), and decreased systemic effects compared with oral or intravenous routes [1, 2, 6].

The inhalation of medication has been dated back as far as the mid-1700s. The common inhaler we know and think of today, the metered dose inhaler (MDI), was introduced in the 1950s by Dr. George Maison [7, 8]. Dr. Maison had an asthmatic daughter. She told her dad that the asthma medication should be more convenient and easier to use than the bulb nebulizer that was available at the time (which leaked in her school bag when she attempted to carry it with her). In 1956, the modern-day MDI was developed by Dr. Maison, Charles Thiel, and Irving Porush [8]. With the development of the MDI, it made delivery of medication and use a lot easier. MDIs are the most common aerosolized medication dose administration device used in the treatment of respiratory disease today. Since the launch and popularity of the MDI, other medication inhalation device types have emerged, most notably that being the dry-powder inhaler (DPI). In very recent years, the soft mist inhaler has emerged and has gained popularity. Today, there are so many devices available and in varying types of medications that it is even easier today for a patient with pulmonary disease to get their inhaled medication than it was just 60 years prior.

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However, ease of use in aerosolized medication dosing does not necessarily equal effective medication delivery to the patient. Many factors affect proper medication delivery to the patient such as age, disease type/severity, administration technique, design, temperature, and humidity. One of the biggest factors may just be that patients often do not take/use their inhalers properly. Studies have shown that errors in inhaler technique may be common, frequent, and repetitive [3, 9–16].

Another factor that can interfere with proper management of lung and airways diseases is the nonadherence to prescribed inhaler therapy [10, 13, 17–19]. Improper inhaler technique and intermittently following prescribed medication usage are common causes of poor respiratory disease control [5, 12, 14, 17, 20]. It has been reported that over 85% of patients may misuse their inhalers either technically or with improper adherence to prescribed dosing [9, 12, 14, 15]. Poor adherence to inhaled medications (underuse, overuse, and improper use) can be nearly 50% in patients with COPD [21]. Poor adherence and poor technique have been significantly linked to poor asthma control [10]. This is, in particular, seen with inhaled steroids since they need to be used consistently to build up to a therapeutic dose. It is common for patients to discontinue steroid therapy on their own because they are feeling better. There have also been studies showing the lack of adherence and poor inhaler technique to be significantly associated with increased rates of admission to the hospital and even a higher risk of death [22]. Today, there are many guidelines for the management of chronic respiratory disorders promoting the use of inhaled medications (such as asthma, chronic obstructive pulmonary disease, and cystic fibrosis). Because delivery of inhaled medications to the lung is so very important in patients with pulmonary disease, we will review several important topics in this area including: examining metered aerosolized inhalation, the various types of delivery devices available, proper techniques, adherence to therapy, barriers to successful medication administration, and what the healthcare professional can do/needs to do to help.

Why Proper Technique Is Important

In typical aerosol deposition in the lungs, medication can be deposited into lung tissue by way of three processes. These include: (1) inertial impact, (2) sedimentation, and (3) Brownian motion [23].

Turbulent airflow created by increased inspiratory flow rates may cause inertial impaction in which much of the inhaled medication dose is lost in the oropharynx and large conducting airways. Although this is more commonly seen with aerosols with particles >10 μm, the throat is the first major site of inertial impaction when medications are given by mouth. Up to 90% of aerosolized medications can be lost due to inertial impaction [23].

Once remaining medications pass the oropharynx and larger conducting airways, medication particles settle in airways due to gravity which is known as sedimentation. Commonly, particles 1–5 μm, which are common to that found in most MDIs and are in the desired therapeutic range for aerosols, are deposited in the lungs due to sedimentation. Since medication particle size is ideal, lung tissue response occurs when medication is deposited via this method. On average, 9% of the total medication dose is deposited by sedimentation [23].

The remaining 1% of inhaled medication enters the lung by way of Brownian motion colliding with adjacent particles as they are free floating. Particles inhaled via this method are <1 μm in size. Due to particle size, they are often exhaled as they are suspended in gas or liquid within the lungs [23].

In vitro studies have shown, even if performed correctly, a maximum of 40% of the medication reaches the intended target of the lower airways [24]. However, most patients with very good technique would fall into about 20–25% range [24, 25]. Those with poor technique drop into the range of under 10% [24]. As discussed previously, most patients perform with some errors, so it likely most patients are getting about 10–20% of the medication from an inhaler to the lung/airways. Since much of medication is lost during a patient's inhalation process, proper administration technique is vital to deliver as much medication as possible to the patient and the lower airways.

The abovementioned medication deposition values are based upon normal anatomy and physiology in healthy lungs. Another consideration is to look at differences in the disease process as well. Studies show patients with severe COPD are likely get a significantly lesser drug deposition in the lung than someone with a mild form of the disease due to inability to generate sufficient inspiratory flow [26]. Therefore, selection of a device that a patient can and will use as well as one with appropriate dosing might be an even further consideration.

Pulmonary disease can lessen medication delivery further due to increased airway resistance, decreased inspiratory volume and muscle strength, airway remodeling, and inflammation [6]. With these added hurdles of pulmonary disease, it makes proper technique vital to deliver inhaled medications.

Medication Dosing Device Overview

Pressurized Metered Dose Inhalers (pMDIs)

Pressurized metered dose inhalers (pMDIs) are the most commonly used MDIs to treat patients with respiratory disease [7]. Their design includes a pressurized metal canister of nonreactive metal, glass, or plastic that allows the medication to remain in liquid form, a metering valve, actuator, dose counter, and a mouthpiece which delivers a precise medication dose (Fig. 13.1). The canister is actuated by the patient to discharge the medication while the patient is inhaling [27]. Particles delivered with a pMDI range from 1 to 5 μm, which is in therapeutic range for aerosol particle size for lung administration.

Propellants are used with the pMDI to deliver the medication dose once actuated by the patient. Before their ban by way of the Montreal Protocol due to negative effects toward the ozone, chlorofluorocarbons (CFCs) were used as propellants. Hydrofluoroalkanes (HFAs) are now commonly used in pMDIs for medication delivery [27].

Fig. 13.1 An example of a pressurized metered dose inhaler

One of the biggest disadvantages of using a pMDI alone is the speed at which medications are discharged. One actuation can discharge medications at a velocity of up to 30 m/sec [28] resulting in more medication lost in the oropharynx. Impaction of the medication often occurs in the cheeks, tongue, or back of the throat. To remedy this problem, valve holding chambers or "spacers" are used to capture medication in a compartment. The medication can then be inhaled slowly allowing more medication to reach lung/airways effectively. Another problem that may arise with use of pMDIs is the need for manual dexterity. Patients with poor manual dexterity and or coordination such as children, elderly, and patients with arthritis may have difficulty actuating the pMDI.

Valved-Holding Chambers

There are many valved-holding chambers (VHCs) or "spacers" available today for use in conjunction with pMDI. To effectively use a VHC, a patient must be able to generate an inspiratory flow rate of 20–60 L/min to effectively distribute medication within the lungs. Lower flows tend to lessen the amount of medication that is drawn from the VHC while higher flows tend to increase medication that is lost in the oropharynx. VHCs are often equipped with a valve that can whistle or hum, indicating too strong of an inspiratory force [27].

As mentioned above, without a VHC, the total amount of medication delivered to the lungs at best is only around 25% [25]. With errors though, the percentage of medicine delivered to the airways drops to half of that. Data that suggests valve-holding chambers enhance pMDI medication delivery is lacking in current medical literature. However, holding chambers may correct for poor pMDI technique [29]. The VHC often can take the guesswork and coordination needed for proper MDI use/administration. It is suggested that VHC be used with anyone using MDIs. Specifically, though, VHCs should be strongly encouraged in the following [2, 30]:

1. Infants/children
2. People prescribed corticosteroids
3. People whom have difficulty with coordinating/timing

In young children (usually 6 and under), a mask is often used in combination with a valve holding chamber, especially when pediatric patients are discharged from the hospital and back into the home setting.

Breath-Actuated Metered-Dose Inhaler

A type of pMDI developed to aide in overcoming the problem with poor actuation and timing, and for use when a VHC is not available, is the breath-actuated metered-dose inhaler (BA-pMDI) [31]. BA-pMDIs actuates at inspiratory flow rates of about 20–30 L/min [2]. By using this method, the patient does not have to time out when to actuate the inhaler. VHCs should not be used with BA-pMDI [2]. Currently, though there are not many medications formulated in this delivery device.

Dry-Powder Inhaler (DPI)

Dry-powder inhalers (DPIs) are becoming more common among maintenance medications in metered dose inhalers as the variety of inhaled medications available continually increase. DPIs use fine particle powder medication formulations that are commonly 1–5 μm in size [27]. DPIs can be seen in single drug types or multiple drugs combined in one inhaler. Medication delivery is created when the patient opens the device to expose the mouthpiece. At that same time as when DPI is opened, a premeasured dose is accessed which is delivered when the patient places the device in the mouth and inhales at a sufficient inspiratory flow rate.

Effective DPI medication delivery is dependent on medication formulae which must be optimized. Inactive excipients are commonly used with DPI medications to decrease medication variability secondary to cohesive forces, most notably, van der Waals forces. Second, DPI device configuration is essential to achieve therapeutic particle range. DPI devices constructed with high internal resistance achieve greater lung deposition of medication [32].

Dry-powder medications, when packaged, are clustered into various sized particles. Medications in this form are not suitable for proper and effective medication deposition in the lungs. Therefore, DPIs must incorporate methods during inhalation to create both uniform and effective medication particle size. DPIs achieve respirable medication particles by way of deagglomeration.

DPIs achieve respirable medication particles by way of deagglomeration. Deagglomeration is a process where these variable size medication clusters are broken down into uniform effective inhalation particles. Deagglomeration can occur in DPIs using 2 methods. First, deagglomeration can occur when medication particles collide with one another or the medication particles can impact the DPI device. Second, optimum medication particles can be created during inhalation by airflow shear to achieve desired particle size [27, 33].

Since no medication holding chamber is needed with DPIs, it is essential that a patient can follow commands and generate an inspiratory flow of 30–90 L/min for optimum delivery. Inspiratory flow greater than 90 L/min can lead to drug deposition in the oropharynx alone. Patients that have inspiratory flows less than 30 L/min may not receive a full and effective medication dose. Some literature questions the effectiveness of inspiratory flow rates from 30–60 L/min [34, 35]. Secondary to this, it has been suggested that maybe greater than 60 L/min to ensure enough inspiratory flow to deliver the powder to the targeted airways [36]. As such, DPIs are not for use with smaller children and these patients are better suited for pMDIs with a valve holding chamber. Many patients are unable to generate the inspiratory flow needed to ensure proper pulmonary deposition and proper drug release [37]. In addition to children, the elderly and those patients with significant airflow limitations will often lack the inspiratory flows needed [37]. Secondary to the flow requirements, these devices are associated with increased resistance during inhalation [16]. Inhalers with decreased resistance have been found to be important to patients and more likely to adhere to therapy [16, 18].

Furthermore, humidity and moisture can adversely change DPI functionality by causing medication to clump preventing deagglomeration during inhalation [7].

DPIs tend to leave a bit more residue in the patient's mouth. This often may cause either a bad taste in their mouth or loss of taste altogether. Some patients also report a dry throat or causing them to get hoarse. All of the above-mentioned can lead to the patient stopping the use of their DPI. There are several types of DPIs out there in use today. In general, though, they come in two formats: single dose or multiple doses. The single type is a where a single dose is placed into the device (Fig. 13.2) and taken each time it is prescribed (for example Spiriva®). The single dose is typically some sort of capsule.

The multiple dose DPI, (Fig. 13.3), is more common and contains several doses (usually enough medication for 1 month of use), for example, Diskus®, Ellipta®, and Pressair®. With the multiple dose DPIs, there is typically some sort of action that opens up a capsule or causes a dose to release. This may be opening/locking of a device, twisting/locking of the device, or releasing a trigger/button.

Soft Mist Inhalers (SMIs, "Respimat®")

Soft mist inhalers (SMIs) eliminate the need for propellants and excipients used in pMDIs and DPIs. Rather, SMIs use spring-loaded canisters that release a predetermined medication dose for the patient, but at a much lower discharge speed when compared to a pMDI. Discharged medications are often referred to as a medication "cloud," which creates a larger window for the patient to properly inhale the medication [28] with decreased oropharyngeal deposition.

Designed to prevent better lung deposition due to lower discharge velocity, there are advantages using SMIs [28]. First, dosing is often cut by half when compared to pMDI. Second, patients with lower inspiratory flow rates can effectively use SMIs. Finally, SMIs can be used in combination with a VHC or a mask can be added to a VHC when used with children.

Fig. 13.2 An example of a single dose DPI

Fig. 13.3 Examples of multiple dose DPIs

Unfortunately, there are limited medications currently in SMI format. SMIs that are on the market at present are approved for COPD use only, although their use in asthma has shown some benefit. Some patients with poor coordination or difficulty with finger dexterity may have difficulty loading the cartridge of the SMI. If a patient shows difficulty with this, it may be important for education of a family member, caregiver, or selection of a different device. Another problem reported about these devices is that it is sometimes difficult to read the dial indicator of how many doses are left. Unlike a counter type of dosing reminder, the SMIs use a number line with an arrow that points to it. Not all the numbers are listed so at times some patients have difficulty reading how many doses may be left.

Which Devices Are More Problematic for Patients to Correctly Use?

Most studies have shown a greater amount of errors among the MDI format compared to the DPI. This is likely due to many more steps required to properly administer an MDI. However, most of these studies have been observational. Some other studies have shown equal observed errors between MDIs and DPIs [4, 38], while others state patients using DPIs made less crucial errors as compared to MDIs [16]. Even some others state that the misuse of DPIs is common, but the significance on clinical outcomes has yet to be shown [12]. There are very few studies looking at the effect of minor errors. For MDIs, there have been problems seen when the medication canister is not properly seated in the "boot" (the plastic device that holds the medication cartridge). When educating patients on use of MDIs, it is important to ensure they have it properly seated in the "boot." If the MDI canister is not properly seated in the boot, a large amount of medication may be lost [39].

It may be very difficult for a patient to determine how many actuations are left on a pMDI. Clinicians should really favor a pMDI with a built-in counter. This will help to ensure the patient knows exactly how much medication is left [20]. Another factor that should be reiterated is for the patient to monitor when a medication will expire. This tends to particularly be true for rescue pMDIs. Patients may not be using them as often as routine controller types of medications.

Patients should be reminded to store DPIs in a dry environment. Also, because moisture/humidity (as mentioned above) may cause the powder to clump, the patient should be instructed to not breathe/exhale back into the device [20].

Checking Proper Inhaler Technique

As mentioned earlier, the inhaler technique and adherence is vital in the management of respiratory disorders (see Chap. 3). One very important part to ensure proper use is to check the patient's technique of their prescribed device. One mistake often made is asking the patient "Do you know how to use your inhaler?" This type of open-ended question without follow-up questions can be deceiving. Often, the answer will be "yes," but without observing the patient to use their device, how does one really know for sure? Or we presume with very simple one-time explanations (and never rechecking) the patient will follow very detailed steps to accurately take inhaled medications and adhere to prescribed therapy [2, 12, 40]. Studies have shown a higher link to inhaler misuse when there has been a lack of quality instruction on correct inhaler technique [4, 38]. Often, healthcare professionals will reiterate the time of dosing without further detail. For example, "Take 1–2 puffs every 4 hours as needed." With this instruction, there are no details of how to inhale the medication (fast or slow), on letting air out first, on a breath hold (and for how long), and no details on how long between each puff. Lastly, one of the most common lack of details was the definition of "as needed." We have frequently been told by patients

Table 13.1 Steps needed to correctly use a pMDI with a VHC

1. Prime inhaler if first use with new MDI or if MDI has not been used in about a week
2. Make sure the canister is properly inserted into the "boot"
3. Remover cap/cover from both VHC and MDI boot
4. Insert the MDI into the back of the VHC
5. Shake the pMDI several times
6. Exhale fully, away from VHC/MDI
7. Place the VHC and attached MDI into mouth (past teeth, above tongue and create tight seal with lips)
8. Press down on the medication container once and release
9. Breathe in slowly as deeply as possible
10. Hold your breath for a minimum of 5 seconds (preferably 10 seconds)
11. Remove VHC from mouth and exhale slowly/gently

that they really are not sure when they are to use an "as-needed" medication. This leads to the patient not using it for fear of overusing it.

One common and inexpensive way is to have a checklist of proper steps and to check the patient's technique face to face [2, 41]. Placebos are really great to use since each inhaler design can be different and has unique qualities and attributes that may need to be tailored for specific patients [2, 41, 42]. Have the patient use a placebo inhaler and check off each step performed correctly. One major focus during these follow-ups is to support the development of a patient's psychomotor skills [17]. First, conduct a demonstration of the proper use with the placebo, then have the patient repeat what they saw [17].

In general, there are several steps needed to correctly use a pMDI with a VHC [25] (Table 13.1):

If more than one dose is prescribed, wait about 30 seconds and repeat steps 5–11.

As mentioned above, there are different types of DPIs and the way the powder is released can be different in each device. Because of these differences, it is always best for the healthcare professional to review the medication/deliver package that comes with the specific inhaler. But in general, there are several steps for the proper use of a DPI inhaler (Table 13.2) [43].

Another important process is to have the patient verbally describe the proper use of their inhaler. As mentioned above there are key steps for proper use of inhaled devices. Having the patient be able to reiterate these steps demonstrates to the healthcare professional that the patient has learned the correct sequence. When teaching or reassessing technique, this way of reviewing to ensure proper use is known as the "teach back" technique/method. This method ensures reverse demonstration as feedback that the patient understood what you just showed them. If the patient does not show back what they just learned, then the educator knows further instruction is required [44]. If the patient has errors, the instructor should identify the problems with the technique, reinstruct, and have the patient demonstrate again [10, 17]. Common errors in technique for the pMDI and DPI are described in Tables 13.3 and 13.4, respectively. The instructor should also have the patient verbally reiterate when/how often the inhaler should be used. *Teach-back* is discussed in further detail in Chap. 5.

Table 13.2 Steps for proper use of a DPI inhaler

1. Open the device (usually some sort of mouthpiece cover/ guard)
2. Load/activate the powder medication dose (varies with each device)
(a) Slide the lever away until it clicks – Diskus®
(b) Opening the device until a click – Ellipta®
(c) Twisting base of device until click – Turbuhaler®
(d) Pressing down the button of the device – Pressair®
(e) Loading a single pill – Handihaler®, Neohaler®
2. Keep device level while inhaling
3. Exhale fully, away from the mouthpiece
4. Put mouthpiece between teeth and close lips around
5. Inhale deeply and forcefully
6. Hold breath for 10 seconds
7. Remove inhaler from the mouth without exhaling into it
8. Breathe out slowly

Table 13.3 Common pMDI and soft mist inhaler errors

No spacer is used with pMDI
Device is not primed prior to initial use
Propellants are not mixed with medication properly (pMDI is not shaken)
Device is not actuated prior to inhalation
Failure to inhale
Inhalation is too fast
Inhaling through nose
Improper length of breath hold (common in asthma)
Unable to tell if medication canister is empty
Medications are not taken consistently as prescribed
Failure to rinse mouth after steroid use

Table 13.4 Common DPI errors

Failure to open slide cover fully to expose mouthpiece / improper cap removal
Poor inspiratory muscle strength to create forceful inhalation
Improper length of breath hold (common in COPD)
Inhalation through nose
Unable to tell if DPI is empty
Improper mouth seal on DPI
Patient exhales into device rather than inhale
Shaking or holding the device mouthpiece downward during preparation
Medications are not taken consistently as prescribed
Failure to rinse mouth after steroid use

The in-check dial type of device is great to simulate to the patient how much inspiratory flow is needed when using an MDI or DPI. Observationally, patients tend to initially inhale too forcefully or fast when using an MDI. With DPIs, the opposite has been observed. Patients tend to not draw in as forcefully as needed to effectively use a DPI.

The Aerosol Inhalation Monitor (AIM) is an electronic MDI training device that can be used to give direct feedback of incorrect inhaler technique. This device can measure key steps needed for effective inhaler use such as inspiratory flow, ongoing flow, and breath-hold [15]. To give visual feedback, the AIM shows a green light to indicate correct inhalation technique. To indicate inaccurate technique, the AIM shows a red light indicator [15]. This device objectively gives real-time feedback to the clinician as well so they do not have to rely solely on subjective analysis [15].

With regard to appropriate inhaler use, a 2011 consensus statement prepared by the European Respiratory Society (ERS) and the International Society for Aerosols in Medicine (ISAM), advised that prescribers check the patient's inhaler technique as well as review the patient's adherence to their treatment plan regularly [2, 12]. Often, the lack of education, with regard to self-management, results in lengthy hospital stays/costly readmissions. It has been estimated that in excess of 25 billion dollars is spent for inhalers annually [40]. Due to misuse of inhalers, it has been estimated that a little over 5 billion dollars annually is wasted [40]. To ensure adherence, it is important the patient be really evaluated so that the prescribed device is something that they are physically able to and will be willing to use [2, 45, 46]. Often, patients prefer something that is easy to handle, small to carry, and is easy to tell how much medication/dosage is remaining [47, 48]. Patient preference and satisfaction with their device should be a consideration when the healthcare worker is determining the best medication/device to use with their patient [48]. Although a patient may be more satisfied with a device and more likely to adhere to the prescribed technique, the technique can still remain poor [2].

Uniformity in Color or Design

In the 1980s, color coding was used among inhalers. Blue was designated for fast-acting (rescue) medications while brown was used for inhaled corticosteroids. All inhaled medications at that time were pMDIs. The obstacle to successfully identify the medication was that the patient had to be able to see the color of the inhaler to confirm it [49]. As new medications emerged, pharmaceutical companies began deviating from color coding. With no uniformity in color coding, a fast-acting inhaler and a combination inhaler might be the same color (because of different manufactures) or a fast-acting inhaler may have three different colors between different manufacturers. Having certain colors/designs universally accepted would be ideal and effective for uniform teaching [50].

There have been proposals that color coding could be successful by using single color decals applied to the medication packaging based upon specific medication type. In MDIs where medication combinations are used, multiple single-color decals could be used to specify individual medications, but again there is concern of those who are colorblind. However, there have been ideas suggested that the Braille system could be fabricated into the inhaler device [48]. A uniform coloring for specific types of inhalers would certainly be a relatively easy/uniform way of patients to distinguish between maintenance inhalers and fast acting (rescue) inhalers.

Cleaning

Inhalers, since they are taken by mouth, are prone to debris and are potential reservoirs for bacteria [51, 52]. Bacterial infections in patients with chronic respiratory disease such as COPD, may serve as a cause for an exacerbation/trigger [53]. Debris is more likely on inhaler devices and is concerning as it may interfere with the proper delivery of the medication [52]. Patients should be instructed to wipe off the mouthpiece with each use. One area of concern when a patient does clean their inhaler is when cleaning a DPI. Care must be taken to ensure moisture does not get inside the DPI. As mentioned before, moisture in a DPI can cause clumping and ultimately loss of deliverable medication to the airways. On MDI inhalers, cleaning the “boot” is important to ensure proper aerosol is dispensed.

Patients should also be instructed on cleaning their VHCs. These can often be cleaned by disassembling them, using hot/soapy water, rinsing and letting air/drip dry. After completely drying the VHC, it then can be reassembled [29]. Patients should be discouraged from wiping or rubbing the inside of the VHC since that can add to the surface charge of the chamber, thus affecting the amount of aerosol delivered to the lung/airways [20].

Barriers and Challenges to Successful Inhaler Use

Multiple Differing Devices and Techniques Most patients using any form of inhalers long-term usually require at least one rescue medication and one controller medication. Patients who are prescribed more than one inhaler are more likely to misuse them. Patients prescribed two or greater maintenance inhalers have shown higher rates of incorrect administration technique [1, 54].

Age There is a direct relationship between the amount of medication deposited in the lung when compared to both age and body weight. That is, as both age and body weight increase, higher doses of medication are received into the lung [55]. A very large barrier exists in younger children as there are limited medications that can be used due to age. Most DPIs require patients to be at least 4–5 years of age to provide adequate inspiratory flow when using a DPI for adequate lung deposition. It is well known to pediatric clinicians that appropriately delivering inhaled aerosolized respiratory medications with any device can sometimes be challenging. Often times, when a child is transitioning back to the home setting from the hospital, they will transition to MDIs since they can be quickly given to the child.

pMDIs tend to be the inhaler device of choice with younger children since they can be given in combination with a mask and VHC. In a study conducted by Ditcham et al. in 2013, results of their investigation show that there was similar medication deposition into the lungs in patients 3–5 years of age when MDIs were given by a mouthpiece device in comparison to a mask [56]. Current medical literature recommendations state that a mask should be used with a pMDI until at least age 3 or until the child can use a mouthpiece effectively [57].

Clinically, it was once thought that when babies cried during aerosolized medication administration, there was more medication deposition in the lungs. Research has proven this to be a false finding, as there is more effective medication delivered to children during quiet and nonstressful breathing patterns [57].

SMIs are another device option in children due to lower medication discharge velocity, as previously mentioned. However, SMIs tend to be limited by medication selection and variety constraints. Common errors associated with both pMDIs and SMI usage are listed in Table 13.3 [1, 17].

DPIs have a much wider medication selection than SMIs. However, in younger children, these medications tender barriers for their use. First, younger children may not have inspiratory flow rates required for proper medication delivery. Second, some DPIs have age constraints. That is, they are not approved for use until the child reaches a specific age.

There also appears to be a barrier to achieving successful MDI use in the elderly population [58–60]. Often, physical or cognitive disabilities more evident in the elderly may also cause a higher rate poor adherence or poor inhaler technique [58, 59]. Another limiting factor may be due to multiple inhaler use and the elderly patients view/approach on health-related topics. Advanced age may also affect lung function and inability to generate adequate inspiratory flow rates as previously mentioned specifically for DPIs [58]. Common errors associated with DPI usage are listed in Table 13.4 [1, 17, 37].

Health Literacy The healthcare professional is not available to monitor their patients 24/7 to ensure they are using their medications appropriately and understand what they must do when. For effective care, and to ensure patients are able to make educated decisions about their health, they need to be able to obtain, understand, and ultimately be able to follow through with the information about their health [61]. One common mistake made is that we overwhelm patients with educational material that is beyond their comprehension. We assume by giving patients as much information as possible that it will aid them in understanding. Not all people learn the same way. In one study, patients with chronic pulmonary disease who had lower educational levels, showed very poor inhaler technique [61], thus reiterating the need for a more personalized training [5]. In order to ensure effectiveness, educational materials should focus on the patient's knowledge. When needed, the patient's knowledge should be strengthened to ensure confidence and competence to ultimate improve adherence [8]. When providing information/education to patients/families, the healthcare educator must ensure that the format used is one that the learner (patient and/or family member) can understand. For example, if written materials are provided, the materials should be at a level that they are able to read and understand written instructions [8]. How to support a patient and/or family member learning is further discussed in Chaps. 3 and 4.

Financial Barriers/Insurance Coverage A frustrating, but common, problem is that healthcare professionals may encounter in some countries is insurance coverage and funding for prescriptions, which occur in all age groups. Either it is too expensive for the patient, or what used to be covered is no longer funded, so they are forced to switch to an alternative medication and inhaler that does not work as well for them. This often leads to confusion or the patient just stops taking a prescribed medicine. Medication assistance programs are often available through various manufacturers. However, the patient and or healthcare professional may be unaware of these programs.

Hospital Formularies With new inhalers continually being introduced into the market, it is unrealistic and impractical for each hospital pharmacy to keep every MDI in stock. Hospital formularies were created to control cost, enhance correct medication use, and most importantly, increase patient safety by reducing medication errors [62]. Maintenance or “controller” medications such as long acting bronchodilators and inhaled corticosteroids tend to be the group of MDIs that vary among hospital formularies. Because of this, a patient may be switched to another brand or type of device/medication during their hospital visit. Some institutions allow the patient to take home their medications after being discharged from the hospital. This creates an additional risk of noncompliance and/or confusion. Now which inhaler do they use? Sometimes patients will use both once they are home, increasing the potential risk of over medication.

Following-Up on Technique

Because the majority of patients do not use their inhalers correctly and many factors can contribute to poor adherence, many guidelines recommend inhaler instruction and review of technique frequently and specifically after follow-up from hospitalization [2, 6]. Also, as disease progression occurs, it may become very important that the patient still has the inspiratory capacity to use certain inhaled devices [63]. One way to ensure the proper technique with inhalers is for clinicians to reassess the technique with every visit [2]. Assessing the technique and reviewing the timing of use should be done at clinic visits, while in hospital, in outpatient settings (i.e., pulmonary doctor’s office, lung clinic, or pulmonary function lab), and in the home setting, with regularity. Ideally this would be every 3 months initially, and then once proficiency is shown and disease management stabilized, maybe every 6–9 months. Often, a common mistake made is that the healthcare professional assumes the patient knows what they are doing because they have had their disease for years. Or we teach it once and assume that the patient has the appropriate technique mastered over the long term.

A key to follow-up care is to identify whether the patient is not using inhalers at all due to medication routine noncompliance versus using them incorrectly. Determining why a patient is noncompliant with the medication regimen is just as important as ensuring they are using it appropriately. Education on disease process and how medication affects progression and symptoms may be a key to ensuring compliance with the prescribed regimen.

One of the barriers to education in the hospital or even in clinic visits is the allocation of time and trained staff to do so. An ideal place for patients to get great exposure to follow-up for technique is in pulmonary rehabilitation (PR). PR programs foster opportunities to review medications, their use, and develop ways to implement strategies that focus on supporting adherence [64]. Unfortunately, patients may not always be referred to, be eligible for, or have access to these programs [64]. To aide in this gap, there has been a trend in the last few years toward having specialists such as disease or case managers/coordinators visiting pulmonary patients in settings such as the hospital and then ultimately in the clinic setting to aide in the education process.

Guidelines also recommend that the technique be checked before switching devices/advancing medications [2]. Patients may often have their own idea/beliefs/concerns of how to best care for their lung health. Addressing these through constant following can ensure patient empowerment and improved adherence/better technique [17].

An emerging trend in healthcare today is the utilization of telehealth to provide care/follow-up for patients. Patients utilizing inhaled medication can be interviewed and their technique evaluated from the comforts of their own home. Thomas et al. demonstrated how an inhaler training program that was setup at home using 3 monthly visits through home video conferencing, positively affected inhaler technique, self-efficacy, HRQoL, and adherence to therapy [65]. Patients with COPD would virtually meet with a pharmacist who provided inhaler training using a teach-to-goal method [63]. Participants completed questionnaires to establish disease severity, health literacy, HRQoL, adherence, and satisfaction with the sessions [65]. Although this study was small (only 41 patients), it did show how beneficial such an approach could be to provide another avenue to follow-up care for inhaler technique and adherence to therapy. One obvious problem to video conferencing follow-ups is that patients with lack of resources or access would be unable to utilize this approach. Nonetheless, this approach is definitely an emerging opportunity, since the use of virtual/telehealth is on the rise in the twenty-first century.

Another emerging technology to help healthcare professionals track patients' use and adherence to inhaler therapy is with the use of "smart inhalers" or remote inhaler monitoring devices [17, 66]. Remote monitoring devices are connected to the inhaler and record the information related to medication administration.

Although these devices are rather expensive, are not available with all types, and require the patient to keep in place when using their inhaler, they do provide accurate data on patient use [17]. Providing healthcare professionals with direct feedback is the biggest advantage of these devices. In a pilot study of COPD patients, Sumino et al. found that over a 3-month period, increased albuterol use captured by the sensor was associated with self-reported episodes of moderate-to-severe exacerbations [66]. This finding can be an extremely important early indicator of an exacerbation, and can be used when following up with patients using inhaler devices.

What Else Can We Do?

Often, patients do not know they are performing their inhaler incorrectly and believe how they use it is the correct way. Reiterating and checking technique in the hospital remains important, but it may not be the best environment to learn and retain vital educational information. As mentioned above, getting involved in the outpatient pulmonary office setting is becoming a greater trend/focus among health systems to ensure patients know how to use, are using, and adhere to their prescribed inhaled therapies. Personalized inhaler technique sheets/labels detailing proper use and highlighting incorrect steps are low-cost interventions that can be used for improved patient education and adherence [17].

At the University of California San Diego COPD/Asthma Education Clinic, one successful solution implemented to help patients with medication adherence was to give them a copy of a common inhalers picture sheet. The inhaler the patient is to use is circled and a brief overview of when it is to be used is written beside it. For example, if the patient is prescribed Albuterol as needed, the picture of the Albuterol inhaler would be circled and beside it is written, “Take for quick relief of symptoms.” If the patient is prescribed a maintenance inhaler, that picture is circled and something such as “takes 2 puffs every 12 hours even if feeling better.” This way, the patient knows not to take it randomly as needed, but routinely as prescribed. The sheet of pictures is printed out in color and has the names of each medication bedside them. Often, patients stated they would tape this sheet on the inside of their medicine cabinet, so they remember what inhaler was to be used when.

At the UMPC Comprehensive Lung Center in Pittsburgh, pulmonary patients started on new inhalers are taught the correct technique, using placebos by a pulmonary healthcare professional. The healthcare professionals utilize teach-back technique to ensure proper reverse demonstration with placebo inhalers. The technique is checked frequently during return visits as well as when prescribed new inhalers. Also, patients prescribed MDI or DPI devices are checked to ensure that they have accurate inspiratory flow rates by using the In-Check Dial device.

Geisinger Medical Center also utilizes teach back technique during education, and incorporates In-Check Dial to assess patient inspiratory flow rates to ensure proper MDI device for patients.

Other Problems Leading to a Lack of Capability for Inhaler Use

Another issue that dampers appropriate education is that all too often healthcare professionals providing education are not properly trained on the use of devices either. There appears to often be a lack of medical textbooks or chapters even including a simple list of steps to properly use an inhaler [40]. Literature has shown that the overall knowledge and understanding by healthcare professionals is rather low and inadequate [17, 67–69]. Some literature reports that over 60% of healthcare professionals (nurses, doctors, pharmacists, and respiratory therapists) are unable to describe critical steps to proper inhaler use [40]. Poor understanding of the correct use of these devices may prevent healthcare professionals from being able to adequately assess and teach proper inhaler techniques in their patients [67]. This calls for organizations to develop guidelines and/or institutions to develop policies/protocols to formally layout how education should/will be performed. This should include guidelines for the healthcare professional as to what should be covered when teaching patients the correct technique. Another factor that may lead to improper education by the healthcare professional is sufficient time for education is not allocated [69]. In some countries, this may be due to a lack of funding or reimbursement for clinicians to provide education. State and federal lawmakers need to also be educated on this important matter to allow for institution reimbursement/funding and to ensure proper training costs are allocated to healthcare professionals.

Conclusion

The inhalation of medication to treat patients with pulmonary disease is common, as well as efficacious. There are many factors that affect the delivery of medication to the airways and lungs. There is also a variety of devices available to deliver these medications. Although these devices appear simple to use, currently prescribed devices are quite complex after being constantly improved for over 60 years to ensure effective therapy.

Nonadherence to prescribed therapy adversely impacts health outcomes, the HRQoL of the patient, and healthcare costs/reimbursements. There is still room for great improvement since inhaler/medication misuse and errors regarding proper use are very common. It is important for both the patient and healthcare professionals to fully understand how inhalers work, and which device is the best for specific patients and situations. Each device can have equal advantages as well as disadvantages, so it is extremely important for healthcare professionals to work together with the patient to find a device the patient is more likely to use and understand.

Ongoing evaluation and training of proper inhalation technique in patients using inhalers to treat their symptoms and manage their pulmonary disease remain extremely important, if not vital. Evaluating and re-evaluating the patient's technique and adherence to prescribed therapy as often as possible enhance the likelihood of successful compliance and disease/symptom management.

Ongoing research and data collection are also vital to ensure advanced education on inhaler technique and to maximize adherence to inhaled medications. As important as inhaled medications are to manage patients with pulmonary disease, it should not be considered acceptable that well over three-fourths of these patients continue to inadequately adhere to therapy or use their device [70].

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Chapter 14
Smoking Cessation: Breaking the Strong Addiction

Enid Neptune, Frank T. Leone, and Hasmeena Kathuria

Introduction

Tobacco use is the leading cause of preventable death, causing nearly eight million deaths per year worldwide [1]. In the United States, smoking cigarettes accounts for 1 out of 5 deaths [2, 3] and is responsible for almost 90% of lung cancer and 80% of COPD deaths [4]. More than 50 years after the release of the first Surgeon General's report on smoking, overall smoking prevalence in the United States has fallen from over 50% among adults in 1964 to less than 15% in 2017, suggesting an immense public health success [3]. However, obscured by this superficial assessment is the observation that the distribution of tobacco dependence within the United States has become segmented. Tobacco dependence rates remain high for the poor, those with substance use disorders, the mentally ill, communities of color, the military, the LGBTQ population, and those without college education, exacting significant disease burden and reduced HRQoL [5, 6]. Of note, these are groups for which tobacco dependence interventions are less available, and health misinformation is widespread [7]. Evidence-based guidelines for tobacco treatment are

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primarily aimed at smokers. Thus, tobacco treatment needs to consider the unique features of the communities that have been resistant to conventional approaches and might respond to more customized strategies. In this chapter, strategies to increase adherence to guideline-recommended tobacco treatment in low SES populations, African Americans, women, and those not motivated to quit are discussed.

Overview of Guideline-Recommended Pharmacotherapy and Counseling

Understanding Nicotine Addiction

Tobacco dependence is a chronic relapsing substance use disorder that is sustained by addiction to nicotine [3]. Nicotine addiction is a complex and highly personalized disorder of learning mechanisms but conforms to known neurobiological mechanisms for drug dependence [8]. By acting at nicotinic acetylcholine receptors, exogenous nicotine mediates brain dopamine release resulting in the reinforcing effects of smoking [9]. Additionally, nicotine engages nicotinic receptors in the ventral tegmental area (VTA), generating perceptions of nicotine-induced reward that becomes associated with the sensory and environmental experience of smoking [9]. This coupling of experience with nicotine changes the structure of the brain, effectively intensifying the predictive certainty of cues. Over time, these cues (specific moods, situations, or environmental factors) can activate the dopamine system on their own and trigger powerful urges to take the substance [10]. As a result, exposure to people, places, or things previously associated with smoking cigarettes can serve as "triggers" or cues that promote smoking, even after quitting.

This concept of nicotine dependence underscores the challenge of quitting in which motivation to smoke is substantially greater than the motivation to quit. Therefore, while nicotine replacement therapies and other pharmacotherapy are one component of a coherent cessation strategy, incorporating behavior modification and redirection of cues that normally trigger nicotine-seeking behavior during abstinence is critical in promoting and sustaining smoking cessation. Vulnerable populations, who exist in a universe of stressors, may display intensified cue- and stress-induced cravings and therefore be at greatest risk for cessation failure [11]. The redirection of these robust cues with tobacco cessation pharmacotherapy plus counseling requires a detailed understanding of the interaction between ambient psychosocial stress and cue-induced nicotine-seeking behaviors [12].

Pharmacotherapy

Pharmacotherapy is considered one of the most effective mechanisms for reducing withdrawal symptoms [13, 14]. The combination of medication with counseling is more effective than either intervention alone [15, 16]. There are seven FDA-approved medications for tobacco treatment: (1) five forms of nicotine replacement therapy (nicotine lozenges, gum and patches can be bought over the counter; nicotine inhalers and nasal spray are available by prescription only); (2) Bupropion (Wellbutrin; Zyban); and (3) Varenicline (Chantix). Second-line treatments include clonidine and nortriptyline.

Nicotine Replacement Therapy (NRT)

Nicotine replacement therapy (NRT) is an agonist at nicotinic-cholinergic receptors. NRT delivers nicotine safely and prevents withdrawal symptoms [17]. Combining the transdermal nicotine patch (provides continuous dosing to produce steady levels of nicotine) with the nasal spray, inhaler, gum, or lozenge (provides "as needed" dosing in response to acute cravings) is more effective in promoting prolonged abstinence than when used individually [15, 16].

Bupropion SR (Wellbutrin; Zyban)

Bupropion SR, a non-tricyclic antidepressant, acts in part as a dopamine re-uptake inhibitor [17, 18]. Bupropion SR is most effective at promoting abstinence and controlling withdrawal symptoms when combined with NRT and counseling [15, 16]. Based on the results of a large clinical trial [19], the boxed warning for serious mental health side effects (including suicidal thoughts, hostility, and agitation) was removed from the drug label in December 2016.

Varenicline (Chantix)

Varenicline, an agonist-antagonist of the α4β2 nicotinic cholinergic receptors in the VTA, has been postulated to work by partially stimulating the VTA while limiting the effectiveness of nicotine as a ligand [17, 20]. A recent clinical trial demonstrated that smokers had more success in quitting cigarettes with varenicline compared to bupropion (OR 1.75, 95% CI 1.52–2.01) or NRT (OR 1.68, 95% CI 1.46–1.93) [19]. Smokers with COPD treated with varenicline did not have an increased risk of neuropsychiatric or cardiovascular events compared to NRT [21]. Combination NRT and varenicline shows the greatest smoking cessation rates [22]. Based on findings from pooled clinical trial data, several large observational studies, and a large randomized trial (EAGLES) [19], the boxed warning for serious mental health side effects (including suicidal thoughts, hostility, and agitation) was removed from the drug label in December 2016.

Counseling

Counseling (group and individual) are both effective if they include practical help that emphasizes problem-solving skills and social support, especially when counseling is intensive rather than brief, and accompanied by pharmacotherapy [23, 24].

Mobile health may be particularly valuable in promoting behavior change. Interactive voice recognition interventions for smoking cessation delivered on programmed and scheduled platforms by an automated service are effective at improving health outcomes and have been shown to be cost-effective [25, 26]. Quitlines provide support for smokers with increased effectiveness when Quitlines include call-back counseling [27, 28]. Interactive texting services that deliver educational and motivational messages about smoking cessation increases 6-month quit rates [27, 29]. To expand access to tobacco cessation services worldwide, a WHO-International Telecommunication Union (ITU) initiative is underway that uses mobile technology to provide tailored, interactive smoking cessation text messages support (mTobaccoCessation) [30].

General Strategies to Increase Motivation, Engagement, and Adherence to Guideline-Recommended Tobacco Treatment to Promote Smoking Cessation

Opt-Out Approaches

Only about 30% of current smokers are ready to quit within the next 30 days [31]. Opt-in approaches require smokers to agree to a quit attempt before treatments are provided while opt-out approaches avail treatment medications and services unless the smoker refuses them. Obviously, opt-in approaches result in fewer smokers who start tobacco dependence treatment but also engage persons more committed to quitting. However, opt-out programs have the potential to engage a much higher number of smokers in treatment, even when commitment to quitting remains uncertain [32]. Several studies implementing a proactive "opt-out" approach to offering guideline-recommended tobacco treatment to all smokers regardless of motivation to quit show both a high acceptance rate and increased smoking abstinence [33–39]. The importance of engaging all smokers in tobacco treatment, regardless of motivation to quit, is supported by previous work that shows, among participants who quit smoking cigarettes, almost half stated that at initial assessment, they were not ready to quit [9]. The clinical decision, therefore, is not whether to offer treatment, but rather how to most effectively facilitate the patient's engagement with tobacco treatment.

Knowledge-Sharing to Address Mistrust and Misconceptions with Pharmacotherapy

Greater medication adherence is associated with increased smoking abstinence [40, 41]. Of smokers who receive prescriptions for smoking cessation, 20% of smokers never fill that prescription [42]. Furthermore, even when smokers receive pharmacotherapy, they will often use them for less time and at a lower dose than evidence suggests is optimal [43, 44]. Reasons for medication nonadherence included perceived lack of need and efficacy of medications to help quit smoking [41, 45]. Additional concerns about the addictive potential and safety of medications for smoking cessation are common. This is not surprising, given that until 2013, labels on NRT packaging indicated that smokers should stop NRT with any smoking and were warned against the combined use of NRT products.

These findings support the need for assessing patient's understanding of tobacco treatment medications and addressing misinformation, particularly given studies showing the efficacy and safety of varenicline in treating tobacco dependence in patients with psychiatric disease [19]. Some studies suggest that enhanced behavioral support interventions that address the practicalities of taking medication and/or changing perceptions about medication can improve adherence to medication and smoking abstinence [41]. Other strategies may include modification of prescribed dose and changing medications in response to adverse effects.

Addressing Low Health Literacy and Stigma

Health literacy is defined as the ability to adequately access, process, and understand health information. Health literacy is a major driver of health behaviors and engagement with the medical system. Low educational attainment, low socioeconomic status (SES), and membership in a minority group have all been associated with elevated risk of low health literacy [46]. In a smoking cessation program comprised of diverse, low SES participants, low health literacy has been shown to be an independent risk factor for smoking relapse [47]. Responses to health risk messaging about smoking were similarly related to health literacy [48]. The use of graphic health warnings and more customized messaging approaches, especially in low SES or immigrant communities, might be productive first steps.

Critical to the steady fall in the prevalence of tobacco use have been the efforts to reduce the social acceptability of smoking, also referred to as denormalization of tobacco use, through propagation of clean air and smoke-free establishment policies. However, the stigma produced by these policies may have counterproductive effects in some cases. Smoking-related stigma is highly perceived among smokers and leads to social isolation, low self-esteem, and shame [49, 50]. The perception also affects readiness for engagement with the medical system and receptiveness to advice about smoking cessation and contributes to population health inequalities [51]. If public health policies and taxation have effectively targeted smokers sensitive to social stigma, the current population of smokers may be those who negatively respond to stigma and require other triggers to quit. Clinicians should approach these smokers with sensitivity when discussing smoking status and actively engage in efforts to minimize stigma associated with continued smoking while finding ways to facilitate engagement through positive reinforcement and social support.

Strategies to Improve Adherence in Specific Populations

Innovative Strategies to Enhance Adherence to Guideline-Recommended Tobacco Treatment in Vulnerable Patient Populations

Inequities in adoption of tobacco control and intervention policies have also led to disparities in tobacco use among the most vulnerable patient populations [52]. Factors such as SES, race and ethnicity, social marginalization (mental health, substance use, LGBTQ, and indigenous communities), coupled with tobacco industry targeting of such groups and low community empowerment contribute to such disparities [52]. Indigenous people additionally suffer from poverty, challenges in accessing resources and population-based mainstream public health messages, and the acceptance of smoking among communities [53]. Policies that impact uptake of smoking initiation and cessation messages should reflect the specific features of the population. For example, studies from Australia, New Zealand, Canada, and the United States show that elements of effective tobacco treatment interventions among indigenous people includes engaging in community consultation to ensure needs and preferences are met, conducting interventions in culturally safe, community-based settings, and ensuring community ownership of programs [53].

What underlies the SES disparities in adherence to guideline-recommended treatment for nicotine dependence? Among low SES populations, the expense of tobacco cessation pharmacotherapies and the limited availability of counseling contribute to the overall reduced smoking cessation rates. This is highly consequential, given that approximately one-third of Medicaid enrollees smoke [54]. Although the Affordable Care Act (ACA) provided coverage for tobacco cessation medications and counseling under the Medicaid Expansion, surprisingly few eligible enrollees knew about or used the benefit [55]. A survey of both Medicaid smokers and healthcare professionals in two states revealed a remarkable lack of awareness of smoking cessation coverage [56]. Additionally, cost sharing and prior authorization requirements in certain state Medicaid plans create further impediments [57]. The elimination of copayments in the Kaiser Permanente health system in Northern California improved the use of tobacco dependence pharmacotherapies suggesting that this modification of the ACA Tobacco Cessation Program could yield measurable benefits [58].

More effective tobacco control programs and treatment interventions are needed for these vulnerable groups of smokers. Adoption of tobacco control programs that change the social norms of tobacco use by making tobacco products less acceptable and available, such as smoke-free policies in public housing facilities and mental health and substance use treatment centers, are needed. The challenge is implementing such programs while not further stigmatizing smokers who belong to groups that are already marginalized, and empowering low SES individuals to view smoke-free policies as critical opportunities to change social norms, reduce secondhand smoke (SHS) exposure, and increase cessation. As discussed below, (1) community-based programs that provide ongoing social support during cessation is one method of making evidence-based cessation treatments accessible for smokers who try to quit in response to these tobacco control policies, and (2) strategies in which financial incentives are used to encourage compliance with smoking cessation regimens have been studied with encouraging results. Treatment tailored to overcome the challenges in this group of individuals may be particularly helpful in motivating smoking cessation and is an area for future research.

Community-Based (Patient-Support) Interventions

Community-level factors such as the high number of smokers and acceptance of smoking in vulnerable populations, as well as the fear of loss of social acceptance among those who quit, can impede the ability of smokers to quit smoking. Low SES individuals are constrained in their choices of tobacco treatment by adverse social determinants of health such as transportation access to counseling and coverage of guideline-recommended treatment. Proactive programs that focus on access barriers and enable the education and treatment of low SES smokers where they live, work, and see their doctors also appear effective in promoting engagement even among smokers with low motivation [59, 60]. Longer-term studies are needed to show sustainable adoption and quit rates among participants in these programs.

Involvement and training of individuals embedded in the community in the design of tobacco treatment interventions have been effective in the most vulnerable patient populations. Such trained individuals, often called community health workers or patient navigators, can address unequal distribution of resources among individuals by providing linkage to guideline-recommended services, resources, and support with the social aspects of smoking cessation within the community. The lived experience of navigators increases their ability to connect and engage with patients. Data from three studies [61–63] demonstrate the promise of patient navigation to promote smoking cessation, with one trial doubling 6-month quit rates [61]. In a study among smokers living in public housing, an intervention delivered by peer health advocates trained in motivational interviewing (MI), basic smoking cessation skills, and client navigation significantly increased 30-day smoking abstinence at 12 months compared to control (14.9% vs 7.8%; aOR 2.98, 95% CI 1.56–5.68) abstinence [64].

Financial Incentives

Several studies support the use of financial incentives to promote smoking cessation. Fraser and colleagues showed that incentive payments for treatment engagement and abstinence (total possible payment of $190) increased very low-income smokers' success in smoking cessation (21.6% vs 13.8%, respectively, $p < 0.0001$) [65]. A randomized trial of low-income smokers in the primary care setting showed that patient navigation combined with financial incentives increased biochemically confirmed

12-month smoking cessation (11.9% vs 2.3%, $p < 0.001$) [66]. Mundt et al. showed that financial incentives to engage low-income smokers with tobacco quit line treatment are a cost-effective option to enhance smoking cessation rates [67]. Together, these studies demonstrate that financial incentives in low SES populations are a promising approach to promote treatment engagement and smoking cessation.

Tailored Treatment

The coexistence of mental illness or substance use with nicotine addiction is common. Smoking prevalence among persons with mental illness and substance use disorder is extremely high, ranging from 30% to 80% depending upon the diagnosis [5, 6, 68]. Multiple myths concerning treatment of tobacco dependence in these individuals are widely believed, even among healthcare professionals (Table 14.1). First, many patients believe that tobacco cessation approaches may trigger psychiatric decompensation and/or substance use relapse [69–71]. Actually, clinical decompensation likely reflects nicotine withdrawal meriting escalation of appropriate tobacco cessation pharmacotherapy. Furthermore, smoking cessation does not delay recovery from mental illness, and smoking cessation may even improve drug abstinence [19, 70–74]. Individual, culturally relevant message framed around the benefits of quitting, such as informing patients that quitting cigarettes may prevent relapse from other substances, may be particularly helpful in motivating smoking cessation in this group of individuals. Second, smoking is often perceived as providing some element of therapeutic modulation to the mentally ill and those with substance use disorders (SUD). Actually, smoking is the primary cause of premature death among these groups [75]. Healthcare professionals need to counsel these patients to correct misinformation about susceptibility and severity of smoking-related illness. Third, healthcare professionals often believe that persons with mental illness and substance use disorder are not interested in quitting and are less able to quit. The reality is that persons with psychiatric diagnoses and SUD have similar interest in quitting as the general population [76, 77]. Efforts to correct these common myths, shared by both patients and healthcare professionals, are needed to improve access to evidence-based smoking cessation therapies in this population with excessive need.

Table 14.1 Myths surrounding tobacco treatment in smokers with SUD and mental illness

Myth	Fact
Tobacco treatment may trigger psychiatric decompensation	Smoking cessation does not delay recovery from mental illness
Tobacco treatment may trigger substance use relapse	Smoking cessation may improve drug abstinence
Smoking provides therapeutic modulation to the mentally ill and those with SUD	Smoking is the primary cause of premature death among these groups
Persons with mental illness and substance use disorder are not interested in quitting and are less able to quit	Persons with psychiatric diagnoses and SUD have similar interest in quitting as the general population

Addressing Disparities in Smoking Cessation in African Americans

Although African Americans initiate smoking later and smoke fewer cigarettes per day than whites, they are disproportionately burdened by tobacco-related morbidity and mortality, including smoking-attributable lung cancer [78, 79]. African Americans demonstrate greater intention to quit and are more likely to make quit attempts in a given year [80], yet they are less likely to participate in or adhere to tobacco treatment and have poorer smoking cessation outcomes than white smokers [7, 80, 81]. Among those who do participate in tobacco treatment, the rates of using smoking cessation pharmacotherapy are lower. Studies suggest that misconceptions about the utility and safety of FDA-approved medications and African American preference for mentholated cigarettes [82–84] contribute to these disparities. Addressing these factors is critical to improving smoking cessation outcomes in this population.

Public Policy to Address Menthol in Cigarettes

Among African American smokers 12 years and older, 85% use menthol cigarettes [84, 85]. Among youth, 94.9% of African American and 51.3% of white youth smokers use menthol cigarettes [85–87]. Studies show that menthol cigarettes have higher nicotine content and tar, and lead to greater nicotine dependence and nicotine intake per cigarette smoked, most likely due to the cooling effect that leads to ease of deep inhalation and cough suppression [88]. Studies in rodents show that menthol has its own pharmacologic profile that facilitates nicotine consumptions by enhancing the reinforcing effects of nicotine [89] and upregulating the nicotinic acetylcholine receptor subunits α4 and β2 [90]. In African Americans, menthol smokers have poorer smoking cessation outcomes compared to non-menthol smokers [91, 92]. The marketing of menthol cigarettes has been heavily targeted toward African Americans, especially toward youth in those communities [93, 94]. The FDA published a report concluding that the removal of menthol cigarettes from the market would improve public health [95]. In October 2017, Canada imposed a nationwide ban on menthol cigarettes, and the European Union is planning to ban menthol in 2020. There is evidence to suggest that banning menthol cigarettes helps menthol smokers to quit [96, 97]. The FDA has not yet imposed a ban in the United States despite 44.5% of African American menthol smokers stating they would try to stop smoking cigarettes if menthol cigarettes were banned in the United States [98]. Hopefully, other cities will follow the example set by San Francisco, the first city in the United States to approve a ban on menthol cigarettes.

Proactive and Culturally Tailored Interventions

When controlling for income, studies show that African Americans may be less likely to complete tobacco treatment than Whites [7, 80]. In the Lung Health Study smoking cessation intervention program, despite equal access to counseling and

NRT, African Americans were less likely to return for follow-up after the first year and had lower smoking quit rates than Whites [99]. Encouragingly, the Veterans Victory over Tobacco study, a pragmatic randomized controlled trial testing the effects of a proactive-care smoking cessation intervention on smoking abstinence rates, found higher smoking quit rates among African American smokers, perhaps due to lack of racial differences in receipt of tobacco treatment services [34, 100].

Internationally, more than 50 countries have publicly funded quitlines, with efforts to increase development and improvement of toll-free quitlines in low- and middle-income countries [101]. Toll-free quitlines (800-QUIT-NOW), available in all 50 states in the United States, may be helpful for low-income patients since many states offer access to free supplemental nicotine products. Previous research indicates that African Americans are more likely to seek quitline services [102], yet have lower smoking cessation rates via quitlines relative to Whites [103, 104]. A current study is testing the effectiveness (6 months smoking abstinence and treatment engagement) of adding a culturally specific (focus on targeted tobacco industry marketing, menthol tobacco products, concerns about pharmacotherapy, focus on religion/spirituality, family and community, African American images, and music), video-based adjunct to standard quitline care that focuses on the specific needs of the African American community [105].

Strategies to Promote Smoking Cessation in Women

The risk of death from COPD, smoking-associated lung cancer, heart disease, and stroke continues to increase among women [106]. The decline in smoking has been greater among men compared to women.

Research suggests that nicotine replacement therapy is not as effective for women as for men, and that women may experience more severe nicotine withdrawal compared to men [107, 108]. Studies show that women metabolize nicotine faster than men [109, 110]; faster metabolism of nicotine may result in lower nicotine blood levels from nicotine replacement therapies (NRT) and poorer smoking cessation outcomes with NRT [111, 112]. A recent study demonstrated higher smoking abstinence outcomes with varenicline over nicotine patch and bupropion in women [113]. The advantage of varenicline over bupropion and nicotine patch may be the result of its efficacy for reducing cue reactivity [114] and sex differences in metabolism of smoking cessation pharmacotherapy (varenicline is minimally metabolized) [115].

Counseling Strategies for Smokers Unmotivated to Quit Smoking

Motivational Interviewing (See Chap. 6)

MI is a method of indirectly improving the value of a patient's intrinsic motivations to quit by minimizing the obstacles to change, with an emphasis on resolving ambivalence and building self-motivation [116]. Even focused versions of MI have been shown to increase smoking quit rates [117–119]. Clinicians engage patients in an exploration of the personal "Relevance" of cessation, the patient's perceived "Risks" associated with continued smoking, anticipated socio-cultural "Rewards" of quitting, and the foreseeable "Roadblocks" to recovery. Clinicians need to be prepared to "Repeat" these conversations as needed to facilitate change [120]. Stylistically, MI is best accomplished when clinicians ask questions instead of giving answers, and when resistance to change is not challenged head-on, but rather reframed into more acceptable steps.

Pre-cessation Pharmacotherapy and Support to Promote Eventual Abstinence

Several other approaches have been used to motivate smokers who are not ready to quit. One such approach is reduction support interventions in which smokers are encouraged to reduce the amount of cigarettes smoked prior to total abstinence. Practice quit attempts and sampling nicotine replacement lead to greater attempts to quit smoking among those not motivated to quit, but did not increase biochemically confirmed abstinence at 6 months [121]. Pretreatment with pharmacotherapy before a patient is ready to quit increases the likelihood of eventual abstinence [122]. Varenicline may require initial therapy longer than the recommended 1-week pretreatment period before exerting its maximum effect [123]. A systematic review and meta-analysis of 14 trials (a total of 7,981 smokers) showed that among patients with no intention to quit, medication plus behavioral interventions designed to reduce the amount of cigarettes smoked significantly increased the long-term abstinence (>6 months) compared to behavioral interventions alone or no intervention [124].

Co-creating Teachable Moments During Clinical Encounters to Motivate Smoking Cessation

Teachable moments have been defined as a "naturally occurring life transition or health event thought to motivate individuals to spontaneously adopt risk-reducing health behaviors" [125]. Clinicians can shape almost any event to create a teachable moment for behavior change [126]. There are multiple, potential teachable moments to promote smoking cessation in pulmonary practice (Table 14.2). The Affordable Care Act's greater focus on prevention, the Centers for Medicare and Medicaid Services' requirement to integrate tobacco treatment with lung cancer screening, and Joint Commission Hospital Tobacco Cessation quality metrics represent a moment of opportunity for healthcare systems to engage in tobacco treatment [127, 128]. Taking advantage of these opportunities to motivate behavior change in smoking cigarettes is critical since treating tobacco dependence improves mortality far more than the available treatments for smoking-related lung disease. A few of the relevant scenarios for these moments are enumerated below.

Table 14.2 Potential teachable moments to promote smoking cessation in pulmonary practice

Lung Cancer Screening (LCS)	Smokers undergoing LCS may have heightened awareness of the feared clinical outcome of tobacco use (lung cancer) and may be more amenable to engage in tobacco dependence treatment.
Hospitalization	Hospitalized smokers may be more acutely aware of the consequences of smoking and more receptive to tobacco treatment interventions.
Lung age	For persons with COPD, the assignment of an elevated lung age may render patients more open to therapeutic interventions to arrest further progression of their underlying disease.
Parents of children with asthma	Parents of asthmatic children may be more responsive to education about the clinical consequences of secondhand smoke exposure and the treatment options for tobacco dependence.

Lung Cancer Screening (LCS)

The adoption of lung cancer screening for long-term smokers is an opportunity to create heightened awareness of the feared clinical outcome of tobacco use (lung cancer) and facilitate engagement in tobacco dependence treatment. A recent study showed that telephone-based tobacco treatment counseling was feasible and efficacious in improving 3-month biochemically verified abstinence in the LCS setting [129]. Other studies, however, show that while lung cancer screening highlights the harms of smoking to patients who are chronic, heavy smokers, the opportunity to leverage LCS as a teachable moment is often missed in clinical practice due to difficulty in integrating tobacco treatment with LCS discussions [127, 130]. Incorporating reminders into practice systems, proactively offering tobacco treatment regardless of motivation to quit, and encouraging clinicians to receive training in tobacco dependence treatment are ways that might overcome such barriers.

Hospitalization

The hospitalization of smokers for tobacco-associated diseases (e.g., COPD exacerbation, cardiac disease, strokes) may also create a “teachable moment.” A clear correlation between smoking and the admitting diagnosis as well as the availability of smoking cessation support from inpatient caregivers enable smoking abstinence upon discharge [131]. Yet, an observational study in the United Kingdom showed that only 28% of smokers admitted to UK hospitals were asked whether they were interested in quitting and only 8% were referred for tobacco dependence treatment [132]. Several studies have shown that both opt-in or opt-out smoking cessation interventions for hospitalized smokers are feasible and effective [35, 133]. Opt-out approaches that begin during hospitalization may be particularly effective given that tobacco use itself is a strong predictor of missed clinic visits [134]. Highest smoking cessation rates have been reported when intensive counseling that begins during the hospital stay is continued with supportive contacts for at least 1 month after discharge [133], amplifying need for close follow-up, expectation management, and contingency planning.

Transitions from inpatient to outpatient management remain a challenge with few services beyond quitlines available in most venues. A study testing a decision support tool triggered upon discharge after a hospitalization for COPD exacerbations increased smoking cessation recommendations from 13% to 92% in an academic medical center [135]. Another study found that automated interactive telephone calls coupled with free smoking cessation medications for up to 90 days post-discharge resulted in significantly higher biochemically validated days and sustained smoking abstinence at 6 months [136]. Of note, the incorporation of a quitline into the post-discharge plan by this same investigative team did not improve self-reported 3-month abstinence suggesting that more diverse and resource intensive armamentarium of post-discharge support tools is needed [137]. The bundling of smoking cessation treatments with other post-discharge interventions such as cardiac or pulmonary rehabilitation might engage more durable health-promoting behaviors [138]. Pragmatic approaches that deliver interventions under real-world conditions are also being studied that may broaden impact across hospital systems and patient populations [139, 140]. Future directions need to focus on (1) transition mechanisms that can be utilized in a resource neutral fashion to ensure long-term (>6 month) abstinence and (2) strategies that can engage hospitalized smokers who are not ready to quit.

Lung Age

Lung age is a recently described metric in which physiologic impairments in lung function are assigned an age designation that is distinct from chronological age [141]. For persons with COPD, the assignment of an elevated lung age can function as a teachable moment in which patients are more amenable to therapeutic interventions to arrest further progression of their underlying disease. Smoking cessation discussions are especially suitable for these moments. Recognition of spirometric lung age facilitated smoking abstinence at 1 year in a single-center single-blinded study [142]. An intriguing study suggested that lung age recognition, independent of impairment, was associated with increased abstinence at 1 year [143]. These findings support the use of lung age as a point of entry for discussions of tobacco dependence treatment.

Parents of Children with Asthma

Children with asthma who live with adults who smoke display greater morbidity with more frequent emergency room visits, higher rates of school absenteeism, and resultant poor academic performance [144]. Even when children receive appropriate asthma management, the existence of a smoker in the home attenuates the clinical benefit [145]. Smoking bans, when enforced in these homes, can mitigate some of the consequences. However, effective bans require intensive counseling of caregivers about the clinical consequences of secondhand smoke exposure and education about available treatments for tobacco dependence [146, 147]. Motivational interviewing plus nicotine monitoring in the home resulted in significantly higher abstinence rates among smoking parents of asthmatic children compared with smoking parents of healthy children [148]. Interventions to reduce SHS exposure should be a priority for clinicians managing any child with asthma, including treating tobacco dependence in parents of asthmatic children [149].

Conclusion

Creating opportunities in pulmonary practice to motivate behavior change in smoking is critical to improving HRQoL and mortality in individuals with smoking-related lung disease (Fig. 14.1). A successful quit program for established smokers requires productive interactions with the caregiver community, sufficient understanding of the biology of nicotine dependence treatment, and a reliable source of critical medications and counseling services. These elements do not all conform to available programs or infrastructures in most medical systems. Below, we enumerate foundational strategies for patient engagement in tobacco dependence treatment. We also discuss customized approaches that provide further enhancement to generic programs.

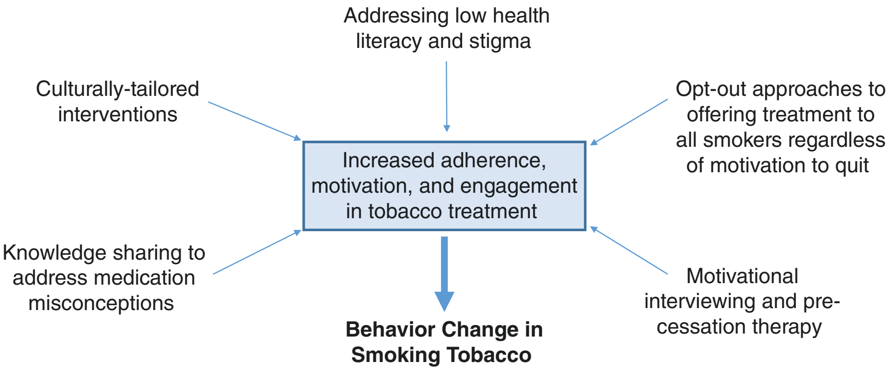

Fig. 14.1 Motivating behavioral change in smoking requires foundational strategies to improve patient engagement (e.g., offering opt-out approaches and pre-cessation therapy to those not ready to set a quit date) as well as customized approaches to improve patient adherence (e.g., addressing stigma, low health literacy, cultural barriers, and medication misconceptions)

Key Foundational Strategies:

1. Take full advantage of the “teachable moments” by providing tobacco dependence treatment at the most receptive encounters.
2. Ensure “opt-out” choice architecture is incorporated within treatment algorithms for high-risk outpatients and hospitalized smokers.
3. Demand that hospital systems provide durable programs, beyond quitlines, that maintain the urgency of the “moment” and can facilitate follow-up within the critical month after hospitalization.

Key Customized Approaches

1. Use data about factors contributing to uptake and success of particular treatments among different populations to inform more customized approaches.
2. Provide materials (written, online, and social media-based) with graphics and text that present tobacco dependence treatment in a clear and culturally relevant manner. Efforts to dispel myths resonant within specific communities should be prioritized. Also, while the neurobiology of tobacco dependence is complex, the experience of compulsion, reward, and cued associations is real and accessible by most smokers. Linking the real experiences to treatment strategy is the crucial message.
3. Explore approaches to improve use of ACA-covered tobacco treatment for low SES smokers.
4. Develop healthcare professional awareness campaigns on tobacco dependence focused on psychiatrists, substance use caregivers, and pediatricians caring for children with asthma. Professional societies could be employed for this purpose.
5. Elevate the narrative of health disparities due to differential tobacco use in the community. Utilize menthol in tobacco products as an example of the tobacco industry’s targeting of African American communities.

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