

Depression and Anxiety in the Patient with COPD

by Jane M. Martin, BA, CRT

Introduction

When Jo-Von Tucker wrote about “The Devastation of the Diagnosis” in her book, *Courage and Information for Life with Chronic Obstructive Pulmonary Disease*¹, she broke new ground with a frank discussion of emotional struggles she experienced in the beginning of and all along her journey with COPD. She then went on to unveil what she called the “Stages of Acceptance,” and two of the nine stages were depression and fear (anxiety).

Historically physician attitudes have not only prevented patients from breaking free of the limitations brought on by emotional issues encountered with COPD, but have contributed to those problems by chiding their patients with remarks such as, “What can you expect? You did this to yourself,” and “Your lungs are shot. There’s nothing more that can be done.” Traditionally patients and family members have perceived physicians as the final word, believing everything they said, therefore accepting the blame for having COPD, and leaving the office with a sense of great futility.

Adding to the blame factor is the problem of a lack of understanding of the mechanism of COPD. Although some recent changes in communication have brought improvements, patients and families frequently lack a clear understanding of COPD. Therefore, they lack confidence when it comes to effective management and the achievement of a good quality of life. The internet has been helpful in this regard, connecting patients to a wider range of information, albeit some unsound practices, devices, and “medications.” Through the internet, pulmonary patients and their families are now encouraged directly or indirectly to seek a second opinion and find state-of-the-art care in specialty facilities. Perhaps most important though, they are able to learn from each other and garner peer support.

So, we have a person with an incurable disease, combined with feelings of blame and confusion and it is no wonder that depression and anxiety rule the day.

Disease and Illness

“Disease refers to a condition of the body. Illness is the way disease interferes with everyday living. Doctors are experts in disease, [but] only [the] patient can experience the consequences of illness,” said J.M. Donaldson.² This can be seen clearly in the following table, in which we can see the enormous contrast between the clinical definition of COPD and the patient’s perspective, paralleling the difference between *disease* and *illness*.

A. Clinical definition³

COPD is a disease state characterized by airflow limitation that is not fully reversible. The airflow limitation is usually both progressive and associated with an abnormal inflammatory response of the lungs to noxious particles or gases.

B. Patient’s perspective

Guilt

Social isolation

Stigma

Disrupted ADL

Financial worries

Hopelessness

Fatigue
Poor quality of life
Impaired relationships
Fear
Depression
Downhill path
Disability
Death
Frustration

A Chronic and Permanent Situation

At a popular annual event held earlier this year for our Better Breathers' Clubs, our special speaker was a three-time cancer survivor who is also a humorist. She is a much sought after speaker in our region, having given hundreds of uplifting presentations. I was looking forward to her presentation and her inspiring words of hope and encouragement to our group. But before her talk she confided in me that she was not really sure what to say to this particular group because her cancer, as trying as it was, had come and gone. Even though it re-occurred, it had been, once again, alleviated and gone. She observed that the people in the audience she was about to address, would have their lung disease for the rest of their lives, day in and day out. That it was not going to go away.

More than anyone else, pulmonary health care professionals must be constantly mindful and sensitive to the fact that although we can "punch out" and go home, our patients cannot. It is, therefore, our job to validate the devastation of a COPD diagnosis which ultimately helps the patient in overcoming feelings that can lead to long-term depression and anxiety.

What Should Physicians and other Respiratory Health Care Professionals Do?

Here are some actions that should be taken by physicians and other health care professionals that can help improve the emotional status of pulmonary patients, and what positive result each action can lead to.

- 1.) Early testing and diagnosis for COPD – **Knowledge of what the patient is facing.**
- 2.) More active statements regarding the unacceptability of the patient's smoking habit. ie: "They're got going to quit anyway, why should I even bother suggesting it?" Having a thorough understanding of the level of addictiveness of nicotine, and the many ways by which people quit successfully. Quitting is not "one size fits all." Research has shown that even a brief mention of the need to quit smoking at a routine office visit greatly improves the chances of that patient attempting to quit.
Empowering the patient that he or she can do something can be done to improve health; that it is not "too late."
- 3.) Having pulmonary rehabilitation as a standard order for the diagnosis of COPD if patients fall within accepted guidelines (and if they don't, be prepared to write a letter of medical necessity), not a last resort for desperate or "difficult" patients as it now so often is.
Empowering the patient to know that he or she can improve the physical state while finding peer support.
- 4.) Suggesting participation in breathing support groups. Every physician should have contact material ready to hand to patients at the time of diagnosis. Would they send a person with a broken leg out of the office and on his or her way without crutches?
Providing information and peer support.

- 5.) Providing each COPD patient with a written personal action plan and the education necessary to help the patient understand how to use it.

Knowledge and empowerment give patients the tools needed to avoid and manage exacerbations effectively.

Improving Patient-Centered Management of Chronic Lung Disease

An excellent paper by M. R. Partridge, “Living with COPD: The Patient’s Perspective,”⁴ sites the importance of a “written personal action plan” which stems from the success of written action plans used by asthma patients as unequivocally concluding that self-management education was effective (46.). However, only two of the eight COPD studies reviewed by Monninkhof, et al included a written personal action plan.

Some programs use a written Action Plan for COPD similar in nature to those used in many asthma management plans. “If you experience ‘A’, then do ‘B.’”

I suggest a more holistic approach be taken, giving participants the means to internalize the tools they possess to make their own decisions when a potential medical problem arises. This further empowers patients and families by requiring them to think through the problem instead of simply following instructions as they would a recipe. In this approach patients take ownership of their care, we might say by learning the art of cooking instead of simply following a recipe.

Breathing Better by making many small changes

The following is something used in one program, working under the premise that many small changes can add up to a big – and positive – difference in life with chronic lung disease. Patients are taught that their breathing and their health will improve if they follow the prompts on the list, making these activities a natural part of life each day. They are taught that they already have within them what they need to breathe and live better, that they are just being given the tools to do the job.

In addition to suggestions included on the list, patients are encouraged to choose a mantra that inspires them to get through difficult times. They are also given the opportunity to add activities of their own to the list, giving them further ownership of their disease management.

No matter what the situation, whether it be a terminal illness or a family tragedy, or such, “doing something,” seems to provide at least some measure of relief from tension and anxiety, and ultimately, leads to at least some degree of control. “*There is something I can do,*” therefore I am not totally helpless, and I have some control over my breathing and my life. More knowledge – more control - less anxiety, and hopefully eventually, less depression.

Teaching patients to simply know where to go (ER, clinic, physician office) to be rescued, and when they need rescuing is not enough. The ultimate goal of COPD patient education should be to help patients develop the skills to rescue themselves, or better yet, to manage their disease so effectively as to avoid needing to be rescued as little as possible or not at all. For most patients, this is not something that can be taught in a one-hour education session, or by reading a handout. It is learned over time through immersion in the wholeness of discovering a feeling of health and well-being through exercise, education, and support. All play a part in boosting self-confidence in each patient’s ability to manage his or her disease.

Many small changes can add up to a big – and positive – difference in your life with chronic lung disease. By making these a part of your everyday life, you will feel better and breathe better.

I use pursed lips breathing with any exertion.

I use diaphragmatic breathing every day.

I do chest mobility exercises every day.

I do stretches every day.

I do some exercise every day.

I use relaxation techniques to relieve muscle tension and anxiety.

I do not smoke.

I know the signs of infection and I call my doctor, should they occur.

I am alert to things that make my breathing worse and do my best to avoid them.

I use my breathing devices for inhalers and airway clearance correctly and as recommended.

I do postural drainage and chest percussion as recommended.

I take my breathing medicine(s) as prescribed. I understand how they work. I know which ones are for maintenance and which ones are for relief. The medicine I should take when I am having breathing trouble is:

I carry my up-to-date medication / health information card.

I eat a well-balanced diet with water as recommended by my physician or dietician.

I take a nutritional supplement if I am at or below ideal body weight.

I have accepted the fact that I have a lung disease and keep a positive attitude. I talk with a supportive person about my fears and bad feelings.

My partner and I share our feelings about my lung disease and work together to make our relationship a warm and satisfying one for both of us.

I work in an honest partnership with my doctor to obtain maximum benefit from his / her care.

My personal mantra for my life with chronic lung disease is:

List your own additional ideas on the other side

The Place of Pulmonary Rehab

There have been several studies indicating that comprehensive pulmonary rehabilitation can help decrease depression and anxiety in the COPD patient. One such study published in the September, 1991, issue of CHEST found that participants in a comprehensive pulmonary rehabilitation program experienced improved well-being, including reductions in depression and anxiety. It was concluded that the rehabilitation program had a significant impact in reducing negative affect and increasing positive affect.⁵

Unscientific Study

Nine patients who completed an eight-week pulmonary rehab program of exercise, education, and support completed pre- and post-Pulmonary Function Status Scale (PFSS) self-tests. The PFSS asks patients to evaluate their ability to perform daily tasks, such as carrying a bag of groceries, ascending a flight of steps, walking a city block, etc. It also asks them to what extent they participate in social activities and also how they evaluate various aspects of their own emotional well-being. Higher scores indicate a better quality of life. In our study, eight out of nine people had an increase in scores at the end of program (the one decreased score involved a patient with intractable multiple system problems that were not resolved by working with several physician specialists). The eight increases in scores ranged from 4-47% with an average of 14% and a mean of 8.5%.

Six Points of Progress to Live Well with Chronic Lung Disease

As a direct result of years of working with and extensively interviewing pulmonary patients, I have developed Six Points of Progress to living well with lung disease. The Six Points take the pulmonary patient from denying that he or she even has a pulmonary problem, through facing the existence of the disease and its ramifications, to ultimately moving forward to be of service to others. These do not directly parallel Jo-Von's nine "Stages of Acceptance," but the two lists do overlap and relate to many of the same principles. Following are the Six Points of Progress, a very brief description of each, and, in italics, what a patient might say in explanation of what they learned in each phase.

Recognition – Getting past denial and facing the reality of lung disease.

My lungs are damaged. Unfortunately, this is a fact, and now I just have to do my best to deal with it.

Validation – The patient's feelings, also, are real and he or she does not have to feel ashamed for being frightened and confused.

I thought I was being a wimp, but now I know It's normal – and expected – for me to feel this way. Who wouldn't be frightened if they were faced with this?

Voice – People with chronic lung disease have the right to be treated with respect and provided with the best medical care available.

I shouldn't be made to feel like a bad person just because I'm on oxygen. I'm still me, and I should be afforded the same types of practical assistance as does any person with a physical challenge/disability.

Education – Having knowledge of specific pulmonary disease is essential to optimal management.

Now I finally understand what happened to my lungs and when you understand what is going on it is a lot less scary.

Support – Peer support is highly important to the health and well-being of the pulmonary patient, and its value should never be underestimated.

I always thought I was the only one, and now I know there are other people just like me. I always feel better when we can get together and talk about it.

Service – Helping others with pulmonary disease and those with other needs actually improves the quality of life and well-being of those in service to others, and some experts claim, even increasing the length of life, itself.

I thought I would never be useful to anyone again, but now I see that there are still things that I can do to help others, and maybe I can do something in some small way to help other people not have to go through what I did.

¹ Courage and Information for Life with Chronic Obstructive Pulmonary Disease. Carter, Nicotra, and Tucker. New Technology Publishing, 1999.

² Donaldson JM. A patient's view of asthma. J R Soc Med 1995; 88 590P-593P.

³ GOLD (Global Initiative for Chronic Obstructive Lung Disease). Global strategy for the diagnosis, management, and prevention of chronic obstructive pulmonary disease. Bethesda, MD: National Institutes of Health. (NIH Publication No. 2701); 2003.

⁴ Partridge, MR. Living with COPD: the Patient's Perspective. ERS Journals, Ltd. 2004.

⁵ Emery, Charles F., Leatherman, Nelson E., Burker, Eileen J., MacIntyre, Neil R. Psychological outcomes of a pulmonary rehabilitation program. CHEST, September, 1991.