

## Compliance Reliance or Compliance Defiance?

### How to go from Compliance to Adherence

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Compliance: According to Mr. Webster, the definition of compliance is “complying, or giving in to a request, wish, or demand.” In medicine this term has been used since the mid 1970’s to mean how well a patient follows physician advice about their medication program. Basically, patients who take their medications as prescribed and correctly are called “compliant,” and those who take their medications incorrectly or perhaps not at all, are “noncompliant.” A number of other terms have been considered as alternatives over the past 40 years. These include **adherence, persistence, and concordance.**

It now appears that the word “**adherence**” has taken the place of “compliance” since compliance” denotes a passive role for the patient. “Adherence” supports a more patient-centered approach to improving how patients seek information, fill their prescriptions, and go on to take their medications as prescribed. Studies have repeatedly shown that not that many patients are as adherent as their doctors may wish. It is estimated that 50% of patients do *not* take their medications as prescribed.

Adherence rates are higher in patients with acute conditions such as Pneumonia when compared to chronic conditions requiring long-term or lifelong therapy such as COPD. It just makes sense that if you have a chronic health problem of any type, poor medication adherence leads to unnecessary disease progression, complications, reduced functional abilities, a lower quality of life, and in extreme cases even death. Because of all these possible consequences, adherence has actually become recognized as the key mediator between your doctor(s) and YOUR medical outcome.

Time for a POP Quiz. Let’s see how adherent YOU are with your medication therapy. There are no trick questions here and all you have to do is answer yes or no.

1. Have you ever neglected to fill an initial prescription?
2. Have you ever neglected to refill a prescription that your doctor wanted you to take?

3. Do you neglect to take your medication(s) on the time schedule ordered by your doctor?
4. Have you ever stopped, skipped, or delayed taking a medication to save it for future use. (That is in case the condition it is used to treat reoccurs)?
5. Have you ever stopped taking your medication(s) without telling your doctor?
6. Have you ever taken someone else's medication(s)?

The more questions you answered “yes” to, the more likely it is you are not taking your medications correctly, which may well affect your health. Some of the statistics are startling and I will just share a few with you to illustrate the severity of the problem.

1. Between 12 and 20% of patients take other peoples medicines.
2. Only 43% of asthmatic patients take their medications as prescribed.
3. Although high blood pressure increases the risk of significant cardiac disease by as much as 400%, just 51% of patients take their prescribed doses of drugs to manage this very manageable condition.
4. Unbelievably, only 42% of glaucoma patients were minimally adherent to their medication program even when told they would go blind if they did not adhere. This number only rose to 58% in those patients who had already gone blind in one eye!

The problem certainly worsens as we grow older. On average, a patient 75 years and older takes right at 8 different drugs per day. Other studies have proven that as many as 75% of patients in this age group do not take their medications at either the right time, in the right amount, or in the right way. This makes sense when you consider factors such as having more than one health problem to treat needing multiple medications, and more than likely being seen by a number of physicians. Couple all that with the possibility of physical and cognitive challenges, and you have a recipe for problems at the *least* and catastrophe at the *worst*. You have to be able to *read* the prescription to *follow* the prescription.

So now that we have identified “adherence” as one of the more important links in the chain, what is the result of “non-adherence?” Economically speaking we all pay for the cost of non-adherence. Recently, studies have calculated that non-adherence costs our health care systems about 100 billion dollars per year. The total direct and indirect costs to our society from prescription drug non-adherence runs about 177 billion dollars per year. By anyone's definition, that's a great deal of money. Since Americans are living longer than ever, it is most likely that we

will be seeing more and more medications for more and more chronic conditions. A number of studies done in the past 15-20 years have identified the most common reasons patients give for not adhering to their medication program as prescribed. The following list is not in any order of importance, but these patient perceptions are listed most frequently.

1. Perceptions about the nature and severity of their illness.
2. Denial of illness and the need to even take medicines.
3. The assumption that once the symptoms improve or the person “feels better” they can discontinue taking their medication.
4. Beliefs about the overall effectiveness of their treatment.
5. Acceptance of taking certain medications for preventive purposes or symptomless conditions such as taking a statin to lower their cholesterol levels.
6. Worries about the social stigma associated with taking medicines. This may be especially prevalent among patients requiring continuous supplemental oxygen and the need to wear a nasal cannula in public.
7. Fear of side effects and especially becoming “addicted” to their medicines.
8. Some patients have extreme fear of needles. This may have special impact on those patients who may need to self-inject their medicines.
9. Lack of confidence in their ability to follow their medication schedule as ordered by their doctor.
10. Some patients are more likely to believe what they hear and see in television commercials and other forms of social media concerning their medications.
11. Some patients are simply too clinically depressed by their chronic disease to be positive about the hoped for outcome.

Blame for non-adherence should not be placed squarely on the shoulders of the patient. If you think of the chain of events from the original writing of the Rx, to the dispensing of the medication from the pharmacy, there are serial errors that can and are commonly made. This begins with the assumption by the physician (or the office) that patients fully understand the prescription just written for them. In a big survey done by the FDA, only 66% of patients said they were told how often to take a new medicine, and only 65% were told how much to take. When the Rx finally made it to the pharmacy, only 31% of the pharmacists could determine how often to take the medication and 29% how much to take. This probably requires one or more calls back to the physician’s office to clarify the order. Put this one clarification order in the context of the approximate 5 billion prescriptions written every year in the U.S., and it is easy to see how we all pay for non-adherence

problems. So there can be problems starting with the physician's office, thru the pharmacy, and on into the patients home.

And let's not forget to mention the government's role in the chain. Federal HIPAA laws make it difficult to disseminate information without prior patient consent. There is also very little funding of research in the area of improving non-adherence. In fact, out of the 18 plus billion dollars allocated to the NIH (National Institute of Health), only 3 million (.00016%) of that money is earmarked for non-adherence improvement research. Considering it costs us 177 billion dollars per year as taxpayers, it would seem we could throw a few more research dollars that way. A small investment could yield huge savings both in dollars and lives.

Let's now begin to discuss how non-adherence affects our patients with chronic lung disease. Let's start with COPD. Most if not all of our patients know that this is an acronym for Chronic Obstructive Pulmonary Disease. It could just as well stand for **Complicated Ornerly Pulmonary Disease!** By any definition COPD is a very *complicated* disease. Forget the pathophysiology for a moment and let's just concentrate on the various medications commonly prescribed for a "typical" patient with COPD.

While the following may seem to apply to COPD patients only, I think a number of these medications cross over to patients with Interstitial Lung Disease (ILD) as well. A good example would be oxygen therapy which I will discuss further on. Stay with me here and maybe you'll see why I say the "C" stands for Complicated.

Generally speaking one of the broadest categories of medications used by COPD patients are known as Beta<sub>2</sub> Agonists. The Beta<sub>2</sub> refers to the specific sites located in bronchial smooth muscle that relax when stimulated, and the word "agonist" just means stimulating the effect rather than blocking the effect. These agents include both short acting agents and longer acting agents. Some of the more well known include albuterol (Proventil or Ventolin), levalbuterol (Xopenex), pirbuterol (Maxair), and salmeterol (Serevent) just to name a few. Sometimes these are called "rescue drugs" because their onset of action is very fast...usually less than 5 minutes.

Another group of drugs commonly utilized are drugs that block some of the pathways that cause bronchoconstriction. They are known as "Anticholinergics" and have been found to be very effective. The best known of these are ipratropium or Atrovent which is a short acting drug, and tiotropium or Spiriva which is a long acting drug. They do not work immediately and so are often given

in combination with a Beta<sub>2</sub> drug. The best example of this combination would be Combivent. In this way you get both an immediate effect and one that kicks in a little later.

The third group of combination drugs combines a long acting Beta 2 drug with a steroid. Over the past 10-15 years much of the research into the pathophysiology of the airways in COPD had concentrated on the inflammatory component of the disease. It has been known for quite some time that Prednisone in any form has pulled many a COPD patient through an exacerbation. The problem with Prednisone is the long, long list of side effects. Finally, after much study a way was found to combine a Beta<sub>2</sub> drug with a steroid preparation that stays almost exclusively within the lungs. In this way you get the benefit of two different drugs, working in two different ways to achieve the same overall purpose...to help you breathe easier. Understand your physician may want to try a steroid inhaler by itself. There are many on the market with Qvar being among the most popular at the current time. Remember inhaled steroids alone are not fast acting drugs.

The next group of drugs on our list are known as the Methylxanthines. The most common of these taken by mouth at home is Theophylline.

Using yet another pathway in the lungs, taking Theophylline works to open up the airways and actually improves the strength of the diaphragm which should make it easier to clear mucus from the lungs. Theophylline also stimulates the respiratory centers of the brain as well. The problem...much like steroids, is a pretty long list of side-effects. Theophylline is one of the few bronchodilators that is actually monitored by measuring periodic blood levels. Theophylline is one of the oldest of bronchodilators in use. It has gone through its ups and down cycles with pulmonologists, but is still used today in concert with all the other classifications of drugs.

What about mucolytics? These are drugs that act on the viscosity of mucus making mucus thinner and easier to cough up and out. These drugs also have a very long medical history of use in patients with mucus management problems. This would include those patients with asthma, chronic bronchitis, cystic fibrosis and bronchiectasis. Your physician may have added a drug called NAC (N Acetyl cysteine) to your regimen. Another popular OTC drug is Mucinex (Guaifenesin). These drugs and other have been studied very well over the past 30 years, and guess what? Sometimes they work, and sometimes they don't. Generally speaking, they are almost always worth a try with everything to gain, and nothing to lose. The only exception may be those patients with transtracheal catheters. Keeping the

catheter clear of mucus is of utmost importance, and Mucinex in particular has been found to be extremely effective in patients utilizing transtracheal oxygen.

And speaking of oxygen...By my unofficial count in all of the categories I just described there are almost 30 different medications that you take by mouth, inhaler, nebulizer, and occasionally by the IV route. There are liquids, suspensions, aerosols, powders. They range from very, very inexpensive... even pennies per dose for generic Prednisone, to very, very high... right around \$60.00 for a Combivent inhaler in the Denver area. There is one thing in common with all of the above mentioned medications. Not one of them has been proven to actually help you live longer. Live better...yes, breathe easier...yes, improve your pulmonary function values...yes, but live longer...a resounding no.

Only oxygen has been proven to increase survival. But just like all the drugs previously mentioned, you must **ADHERE** to the prescription as written by your doctor. Oxygen is commonly overlooked as the drug it is. Whether you comply or adhere...oxygen is the only drug that once prescribed is going to help you far more in the long run than any of the other drugs we just talked about. So of all your medications, by far oxygen is the most important. Therefore, you must be extra diligent in your oxygen adherence.

You must wear your oxygen at the correct liter flow, for all activity levels to maintain your oxygen saturations in the normal range, and do it 24 hours per day. This is so much easier said than done. If cosmetic concerns prevent you from wearing your cannula out in public for whatever reason, you may wish to investigate the Oxy-View eyeglasses. The only way to *absolutely* insure true 24 hour adherence to oxygen therapy is by the transtracheal route. While many patients are totally adherent to wearing their oxygen 24 hours a day, major studies have proven beyond a doubt that by far, most patients can't or won't do just that.



Pt. with nasal cannula



Same pt. with TTO catheter in place



Pt. wearing Oxy-View eyeglass frames

Although in total it can seem overwhelming at first, there are some things you can do to improve adherence with your medication regimen.

1. Make sure you know both the generic and brand names of your medications.
2. Don't be afraid to ask your doctor exactly why you are taking the medication and how is it supposed to be helping you.
3. Always ask how often, and when during day you are supposed to take it.
4. Find out how long you are to take the drug and what you should do if and when you begin to feel better.
5. Always ask if there are any foods, drinks, activities, or any other medications you should avoid while taking your prescription.
6. Make sure you know what the possible side effects are and what to do if they happen.
7. Feel free to use the internet to find out even more about the drugs you are taking.
8. Try to incorporate taking your medications into your daily routine. This can be based on things like brushing your teeth, when you take your meals etc.
9. Use one of the many pill organizers sold over the counter in supermarkets, and pharmacies to simplify your week or even month.
10. If you notice you are experiencing any side effects, don't hesitate to call your doctor so your situation can be properly evaluated.
11. Don't forget to use your pharmacist as a reference especially on drug interactions.

A final thought on oxygen therapy. Just as the pharmacologic industry has responded with so many new drugs to treat lung disease over the past 20 years, so has the oxygen industry. New oxygen delivery devices are coming on to the market just about every year. This is a good thing. The more options you have, the better you will be able to fit that particular product into your lifestyle. Just be careful and remember that oxygen does not come in a "one size fits all" configuration. Like buying a new car, kick the tires of a new POC, stationary concentrator, or conserving device before your buy. Take each piece for a test drive before making any final decisions. Don't ever, ever forget oxygen is the only drug you will ever take that will not only improve your quality of life, but also the quantity of life...and isn't that what life's really all about?