



The Science and Art of Patient Adherence

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The Science and Art of Patient Adherence

The majority of healing happens outside the clinic. Help your patients improve or maintain their health by understanding the research behind patient adherence. This paper explores research around patient adherence to medication and home treatment programs and suggests how technology can help improve adherence.

Lack of patient adherence to home treatment programs costs the United States upwards of hundreds of billions of dollars annuallyⁱ. The most quantifiable costs come from medication adherence; however, adherence applies to all facets of patient treatment. Adherence is basically how patients live their lives the 99.9% of the time when they are not in your office. Are they following instructions? Are they looking after themselves according to your recommendations?

Quality healthcare outcomes depend upon patients' adherence to recommended treatment regimens. Patient non-adherence can be a pervasive threat to health and wellbeing and carry an appreciable economic burden as well. In some disease conditions, more than 40% of patients sustain significant risks by misunderstanding, forgetting, or ignoring healthcare advice. ii

The key to improving adherence is investigating why patients are misunderstanding, forgetting, and ignoring healthcare advice and then designing treatment programs that address these key issues. Research shows that there are many factors both physical and emotional.

As part of our ongoing research to ensure Wellpepper is addressing these factors, we interviewed and surveyed healthcare providers and patients, we've found provider attitudes to adherence to home treatment programs vary widely from defeatist to defiant:

From "I know they aren't going to do their program when they get home" to "My patients are all adherent, I don't have a problem."

We've noticed that providers have wide-ranging backgrounds and competencies in behavior change factors. Some are experts at helping patients make change, but behavior motivation does not seem to be standard curriculum in healthcare education.

From patients we hear good intentions, confusion, and laziness. Usually they tell us that they thought they understood their programs, or that they thought they would make time for the program but lost some momentum when they got home. A frequent refrain is "*It was so clear when I was in the office.*" We also hear that they didn't want to waste valuable expert time by asking "dumb" questions about their home treatment.

Technology is not a panacea to this problem. However, technology has the ability to reinforce and amplify factors that contribute to patient adherence, mobile technology in particular because of the attachment and relationship we've developed with our blinking, beeping, and demanding mobile devices.



This paper explores the art and science of patient adherence, providing a summary of the patient adherence research and explores how it can be applied to technology to help patients get better outcomes and results. While much of the research is based on medication adherence, these factors, especially when coupled with an exploration of behavior modification, can be applied to adherence to any type of treatment plan.

Why Patients Aren't Adherent

Just as no two patients are identical, the factors that affect adherence vary dramatically from patient to patient, and between types of treatment plans. For example, adherence to medication is often affected by the medication itself: side-effects, contraindications, timing, and the way it is applied. Adherence to a physical rehabilitation program is affected by the function of the patient, very often by the level of pain they feel, and sometimes by the patient's own belief in their abilities to complete the program. Adherence to diet is affected by a myriad of factors including access to appropriate food and peer or social pressure. Even with these differences, however, there are a number of common factors that affect patient adherence, both negatively and positively.

The 2008 study "Factors affecting therapeutic compliance: A review from the patient's perspective"ⁱⁱⁱ provides a comprehensive review of research on the subject, and presents this view of the factors:

Factors related to adherence

Patient-Centered



- Demographic factors
- Psychosocial factors
- Patient-prescriber relationship
- Health literacy
- Patient knowledge
- Physical difficulties
- Tobacco smoking or alcohol intake
- Forgetfulness
- History of good compliance

Healthcare System



- Lack of accessibility
- Long waiting time
- Difficulty in getting prescriptions filled
- Unhappy clinic visits

Therapy-Related



- Route of administration
- Treatment complexity
- Duration of the treatment period
- Medication side effects
- Degree of behavioral change required
- Taste of the medication
- Requirements for drug storage

Disease



- Disease symptoms
- Severity of the disease

Social & Economic



- Inability to take time off work
- Cost and income
- Social support

<http://www.ncbi.nlm.nih.gov/pmc/articles/PMC2503662/pdf/tcrm-0401-269.pdf>

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As a provider, there are some areas that you can influence, and some to consider as input to inform how you approach the patient. For example, you probably can't impact their socio-



economic situation, but you can understand how it might impact their treatment. For example, is cost a factor in their ability to adhere to a program? Trying to save money often results in patients trying to take fewer pills than prescribed. We spoke with one arthritis researcher who prescribed swimming for her patients; however, for many of them the cost of a gym membership and transportation to the pool was prohibitive.

Understanding the Factors that Impact Adherence

It's almost impossible to talk about the factors that make patients less adherent separately from the factors that make them more adherent due to the simple fact that they are often two sides of the same coin. For example, if a patient who doesn't understand his program is less adherent, a patient who understands his program is more adherent.

Let's dive into some of these factors, in particular with a view to how they affect adherence to a home treatment program, other than simple medication adherence, for example, pre- and post-operative care for a knee or hip replacement which may involve pain medication, activity, wound care, and a specific set of exercises.

Understanding

Sometimes a lack of adherence is caused by a simple lack of understanding or misunderstanding of the treatment plan. Verbal instructions might be misheard, and patients are often afraid to ask questions. Many patients we surveyed said that they thought they understood the program but only realized when they got home that they didn't. This is frequently the case with exercise programs or medication.

Health literacy is the degree to which a patient can understand the treatment program and is a fundamental building block to adherence. It's impacted by the way the instructions are given as well as the patient's background and prior experience. Patients often don't understand their program simply because they don't have background experience, especially with complex drug regimens and exercise programs. Patients we surveyed reported that they were often intimidated to ask questions or that the form factor of instructions (scribbled notes) often weren't clear enough.

“In practice, patients’ low health literacy has been linked to ineffective physician–patient communication and, in particular, physicians’ failure to assess recall and comprehension of new concepts with their patients.” (Schillinger et al 2003)

Making sure patients have a clear, easy-to-follow plan that does not rely on a high level of health literacy or acronyms is key. Also think about whether the amount of information can be limited. Studies show that when patients are presented with a large amount of information they are more likely to forget it.^{iv}

“Both patients and physicians tend to overrate patient comprehension of medical information and treatment plan recommendations.”^v



Complexity

Complexity of course is related to understanding, however, it can also affect motivation to adhere, in that a patient may be less motivated if she feels that the program is more than she can handle.

The complexity of a treatment course is believed to have an impact on patient adherence, although, this is within certain parameters. For example, for drug adherence, it's found that it's not the number of drugs that increases complexity^{vi}, but complexity regarding the times of day and contraindications can decrease adherence. With Wellpepper users, we have found that there is a positive correlation between number of exercises assigned and adherence, which at first glance seems counterintuitive, however like medications, a greater number of exercises does not necessarily mean the program is complex.

Time

No matter how short a program is, for example, taking a pill, it still requires time. Time can also be related to both understanding and complexity. Does the patient understand why it is important to complete the program at a certain time of day? Does trying to do it at this time of day add to the complexity of the program for the patient?

Time is also a factor when the program has consequences for other activities in the patient's life. Take this example from Jeffery K Aronson, Editor in Chief British Journal of Clinical Pharmacology

'This 81-year-old lady's heart failure is getting worse, with increasing peripheral oedema, despite maximal doses of a wide range of medications, listed below. Please advise.' The problem turned out to be very simple, as her daughter explained when she brought her to the clinic. **'She won't take the water tablets, doctor,'** she told me. Her mother liked to take a stroll outside in the mornings and stay indoors in the afternoons to watch her favourite television programmes. The morning diuresis made that impossible. And since her heart failure had become worse the daily strolls had become more difficult as well. I suggested that she take the furosemide in the afternoons instead.

In this situation, time was a factor related to how the treatment affected the rest of this woman's day. In a rehabilitation scenario, an exercise program might tire a patient and therefore she might want to postpone it until after other activities, or skip it on a day when she knows she needs energy for other physical exertion.

Fear/Pain

With any injury or surgery there will be pain, which is often a deterrent to activity. Kort, et al found that "increased pain levels during exercise are strong predictors of poor adherence."^{vii} One hospital we spoke combats this by making sure patients start their program immediately post knee and hip replacement under supervision while still on powerful painkillers. This kick-starts the habit and helps with mobility so that when the patient decreases the pain medication dose they experience less pain through movement.



Patients often feel pain and quit their program, even though the pain may be at a level that is perfectly acceptable given the situation. This is also related to the topic of understanding: does the patient know what level of pain is acceptable and when they should seek medical advice?

Forgetfulness

“Forgetfulness is a widely reported factor that causes non-compliance with medication or clinic appointments”^{viii}

Forgetfulness can be a factor of our increasingly busy lifestyles, but it’s also often related to routine. Patient’s routine does not include their home treatment program, and they need cues to add this habit.

Short-Term vs Long-Term Gains

This area is probably the most closely related to behavioral science, where the natural human tendency is to do things that are bad for us in the long run for short term pleasure. According to behavioral economist Dan Ariely, even when presented with evidence, like texting while driving increases your risk of death ten-fold we still do it: “The basic issue has to do with succumbing to short-term desires and foregoing long-term benefits.”^{ix} Physical rehabilitation is almost entirely short-term pain for long-term gain, so the deck is naturally stacked against patient adherence. How can you add short-term rewards or goals into the overall program to increase adherence? Many therapists use functional goals that are very tangible coupled with the patient’s long term goal to help overcome this tendency.

Belief system

Research has shown that what a patient believes with respect to their illness or their treatment program impacts greatly their adherence to that program. If a patient believes that there is no hope for improvement for example, in the case of an osteoarthritis patient, they may be less adherent. Or if a patient incorrectly believes that a wound needs to receive air to heal, they may not follow the prescribed care regimen. The degree to which a patient feels engaged and responsible for their own care is also a factor in adherence. Patients who had a lack of confidence in themselves or the impact of the treatment program were also less adherent.^x

With knee and hip replacement, patients come from all types of situations and some may be more motivated than others. In the case of bariatric patients whose need for a knee or hip replacement stems from excess joint strain due to weight, many hospitals will not operate until the issue with motivation and behavior change has been solved.

History and Experience

While the media loves a great story about a turn-around, for example dramatic weight loss, past history and experience is often a predictor of future results. One study on knee and hip osteoarthritis found that:

“Patients with a history of being physically active, a positive view of exercising, good social support, and/or easy access to exercise facilities are more likely to adhere to an exercise program.”^{xi}



Understanding the background of the patient and their previous experience with the types of tasks you're assigning in the home treatment program can definitely help.

Costs of Care

Costs of care are related not just to direct costs to the patient, but also opportunity cost. Just because a patient has insurance coverage for their treatment don't assume that there are no costs to them. Costs include the time required to adhere to a program especially if they need to take time off work, as well as often travel costs in getting to the clinic for follow-up. In rehabilitation therapy in particular, we've heard examples of patients discontinuing treatment because they didn't want to or couldn't spend the time or money to see their physical therapist 3 times a week.

Ownership and Accountability

"One of the major reasons for patients' gap in recall and understanding is that patients are frequently not treated as active partners in their care."^{xii}

If patients feel ownership of their plans, that is the plan is personalized to them, and they are also part of the important decisions about their care, this can improve adherence.

This can be as simple as choosing the times each day when they will complete the program based on their own schedule or preferences^{xiii}. As well, accountability whether to a healthcare provider or their care team, including friends and family can make a big difference. Knowing that someone will be checking up is a key motivator.

One study found that "Prolonged provider supervision strong factor in compliance."^{xiv} In our Wellpepper patient surveys patients cited that knowing that their healthcare provider would review results as a key motivator to increase adherence.

Patient/Provider Relationship

In addition to the accountability that the healthcare provider can provide for the patient, the supportive relationship between patient and provider is a key factor in patient adherence. This relationship must include trust and empathy.

Studies have found that compliance is good when doctors are emotionally supportive, giving reassurance or respect, and treating patients as an equal partner^{xv}

The good news is that increasing trust is relatively easy: making eye contact and asking questions were shown to improve the trust the patient felt for the healthcare provider.

A study from the University of New Mexico identifies some characteristics of fitness professionals that increase their client adherence to fitness programs, many of which could be applied to rehabilitation programs or exercise programs for bariatric patients.

A	ASSESSMENT	Assess all medications
I	INDIVIDUALIZATION	Individualize the regimen
D	DOCUMENTATION	Provide written communication
E	EDUCATION	Provide accurate and continuing education tailored to the needs of the individual
S	SUPERVISION	Provide continuing supervision of the regimen

xvi

The Big Picture of Adherence

Each of these factors on its own has some simple solutions, none are insurmountable. However, considering the inter-dependence of many factors for example the impact of the patient/provider relationship on understanding, as well as that no two patients are identical, it can seem like a daunting task to improve adherence.

At Wellpepper, we've based our product design and development on some basic principles of adherence that are well described by this excerpt from "The Challenge of Patient Adherence" by Martin, Williams, Haskard, DiMatteo.

While no single intervention strategy can improve the adherence of all patients, decades of research studies agree that successful attempts to improve patient adherence depend upon a set of key factors. These include realistic assessment of patients' knowledge and understanding of the regimen, clear and effective communication between health professionals and their patients, and the nurturance of trust in the therapeutic relationship.^{xvii}

There is no silver bullet, but using a number of techniques together can affect positive change. One study concluded that a number of factors together would be most effective in improving adherence.

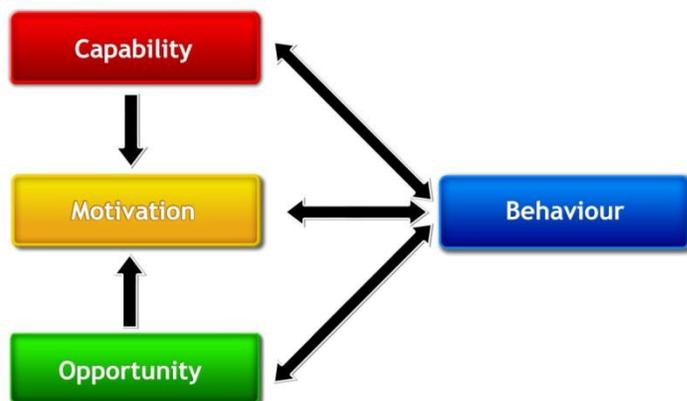
Specific strategies which could be combined were more convenient care, information, reminders, self-monitoring, reinforcement, counselling, family therapy, psychological therapy, crisis intervention, telephone follow-up, supportive care, home visits, education and work site visits^{xviii}

Note the number of interactions in the previous list, and consider that the list will be different for each patient. With ever-shrinking patient/provider face time, how can anyone expect the message to clearly travel from provider to patient, and then affect positive change in that patient? Some basics of behavior change theory can certainly help, as well as trying to spend a few minutes getting to know the values, beliefs, and goals of the patient. If you think of the example of the 81 year old with heart failure referenced previously, knowing that taking a morning stroll was an important value to her enabled her physician to adjust her treatment program, increase her adherence, and ultimately improve outcomes.

Incorporating Behavior Change Basics

Once you understand the factors for your patients that will help them be more adherent, applying some principles of behavior change to those factors can help even more. The very nature of treatment programs being a new habit, necessitates changing patient behavior. Add to that that new habit may take time, cost money, and cause discomfort, and you need to consider all the tools in your toolbox.

Similar to adherence research, there are many theories on behavior change, and the topic will continue to attract and fascinate researchers. We like this simple view from the “COM-B” system^{xix} that in order for someone to change they have to be capable, motivated, and have the opportunity to change.



Think about how this applies to a rehabilitation home treatment plan. First consider whether the patient is capable of doing the program? Can they complete the program without your instruction? One physical therapist told us that on second visit he asks the patient to demonstrate their program. If they can't do it, he knows they haven't been doing it at home.



While this is clever, time has already elapsed when the patient has not started to add this new habit.

Second, is the patient motivated to do the program? What is the patient's goal in recovery? Setting a goal and making sure you are able to help the patient in progress towards that goal are key to recovery.

Third, do they have the opportunity to change? Specifically, do they have time to do the program you assigned? Do they have a location in their home or office where they can do the program? Just asking a patient to tell you where and when they will do their program helps them take ownership for their behavior change.

Bringing it Together: Technology and Behavior Change

Technology, and especially mobile technology, has great power to change behavior: just look at all of us walking off piers or into traffic while glued to our mobile phones. Also consider how many times a day you check email or Facebook. These behavior changes came about from intrinsic motivators in the technology, like rewards. The most addictive technology has these built-in rewards. For example, on Facebook it's how many "Likes" on your post. Twitter has follower counts, retweets, and favorites. We feed these social media beasts for these rewards. Your mobile device offers connection to others and we're constantly checking to see who messaged, emailed, or phoned us.

The great promise of mobile health is the ability for technology-induced behavior changes to take advantage of these intrinsic rewards and motivations that we've already been trained to use to positively influence individual's health. However, technology alone is not the answer. Technology when implemented as part of a larger program that takes into account the factors that impact each patient can support real change.

Looking at the factors that influence adherence explored earlier in this paper, and taking advantage of the connection we have with our mobile devices, delivering mobile treatment plans can be used to address some of these factors.

- Providing a copy of the treatment plan that is always with the patient, and includes video for an exact copy of what was prescribed to improve understanding
- Providing notifications and reminders when it's time for the program to address the problem of forgetting
- Strengthening and enhancing the patient-provider relationship by enabling outside the office communication

This is just the beginning. Technology can also 'learn' what types of reminders, rewards, or motivational cues are most appropriate for each patient, and tailor the experience. As well, patient's interactions with these mobile treatment programs can provide valuable information to care providers about their progress, recovery, and also what types of interventions are most effective both for individual patients and by comparing groups of patients.



At Wellpepper we are inspired by our ability to work with you to be part of this process. We provide capabilities that help patients, particularly in the area of making sure they understand their treatment plans, and are able to complete them and by facilitating the relationship between you and your patient, that is, extending your positive reach and influence beyond the in-person visit. Together we can help patients be more adherent and stay well.



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