Protecting our clients with chronic mystery illnesses

By Katie Playfair, LPC

My husband and I rarely gravitate towards the same types of TV shows so when *Afflicted,* a documentary series on people living with chronic mystery illnesses, appeared on Netflix, we jumped at the chance to watch something so relevant to both of our professional lives. He’s a physician and I’m a counselor and we both see quite a bit of health-related suffering in our practices. *Afflicted* prompted so many conversations between us on how to improve our healthcare system to better serve clients suffering from these mystery conditions but the topic I want to focus on today is the vulnerability of these clients to exploitation by healthcare practitioners and our roles as mental health professionals in protecting them.

Nearly every person highlighted in *Afflicted* had suffered significant financial losses as a result of pursuing treatments for their chronic mystery illnesses. Certainly, some ethical healthcare practitioners were featured on the series but in many cases, as we listened to the assessments, diagnoses, and treatments doled out by (sometimes) licensed medical practitioners to these patients, we were in shock. The basic “science” they presented to support their care was often patently false and the treatments cost thousands of dollars of out of pocket expenses. We were literally shouting at the TV as we watched some scenes, saying “No no please don’t do it! That’s not going to work… They’re stealing your money!! No!!!” Fortunately, in my private living room, I’m allowed to call out BS science, shout at people I disagree with, and I have an MD sitting next to me to error-check my assessments of validity of treatments. In my office, I am operating under a license to practice COUNSELING, not medicine, I don’t have a physician to consult on a whim, and I have a real, vulnerable client in front of me who is desperate to find relief from their suffering. So what can we do in our official capacity as mental health practitioners to protect these clients from harm?

Here are my tips for working within our capacity as mental health care practitioners while helping protect our vulnerable clients:

1. Don’t focus on whether the illness is “real” or “just” Illness Anxiety Disorder (IAD). It doesn’t matter how medically “real” your client’s condition is. Anyone who is relentlessly pursuing medical treatments from many different practitioners needs your support in living with a chronic illness and with not ruining themselves financially in doing so. Feeling stuck "being sick" 24/7/365 is the real problem. Sufferers of IAD have stopped living life, whether they’re “medically sick” or not and this is ultimately the clinical problem we want to address.
2. Encourage/insist your client to find a primary care physician (PCP) who is board certified in Internal or Family Medicine, that they trust. Preferably, direct them to clinics who use a “Medical Home” model of care, which often includes medical social work support, sometimes psychiatric prescribing services, and more case management than a regular medical clinic. Establish communication with the PCP’s office. Traditional PCP services, referrals, and recommendations are more likely to be covered by insurance so they’re an essential part of your team. Traditionally trained MDs and DOs are also very good at doing a thorough medical workup of all the really scary and deadly stuff that might actually kill your client and not just reduce their quality of life. In fact, I INSIST that all clients with chronic diseases and/or IAD, get a thorough traditional medical exam and affirmation from their PCP that easily diagnosable and treatable conditions have been ruled out. The PCP can also be your approver of treatment plans that may require reduced engagement in medical treatment activities. They are licensed to answer the question, “Is it safe if my client…” This protects you ethically and legally. This does NOT mean that your client can’t pursue other treatments from other types of practitioners. We just want one very qualified medical professional to be aware of everything the client is doing for their health.
3. Cultivate awareness and mindfulness about the time, mental energy, and financial costs of their pursuit of treatment. Clients with chronic mystery illnesses are often not completely aware of just how much they invest in disease management. Keeping them mindful and oriented can help them make better decisions about the costs and benefits of further investment.
4. Focus on reengagement in valuable life activities rather than disengagement from disease-management activities. Stopping disease-management activities that aren’t serving the client (as approved by the PCP), is very difficult. Like any safety behavior, doing less is terrifying. So doing less can be more easily done in the context of trading the time, money, or energy for something else very valuable to the client. Doing less does not mean not attending to the chronic disease – it means making a cost/benefit decision on various treatments and planning for a sustainable pace of medical treatment, knowing that for many mystery chronic diseases, the road is years, not weeks long.
5. Watch out for clues that your client is being preyed upon financially:
   1. Be aware of treatments that the client is paying for out of pocket that aren’t covered by insurance. This is a warning sign to pay attention to but it doesn't automatically mean the practitioner is predatory! Some emerging treatments do not yet have enough evidence to warrant widespread use or to make it on an insurance company's "covered services" list but they end up being totally legitimate. For example, there is growing evidence that [sub-anesthetic doses of ketamine may be helpful for treatment resistant unipolar and bipolar depression.](https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4592658/) Yet, while many [insurance companies don't cover it yet](https://www.uhcprovider.com/content/dam/provider/docs/public/policies/comm-medical-drug/ketamine.pdf), you can find evidence that insurers are considering the evidence at hand and may cover it in the future. A non-predatory practitioner will explain uncovered costs and give you the opportunity and resources to help clients advocate with their insurance company for coverage. They'll also often have programs for people with financial need to prevent the treatment from ruining clients financially.
   2. There are no peer-reviewed studies demonstrating the treatment's effectiveness. If a practitioner is relying on "in my experience," as opposed to studies that have been published in peer-reviewed journals to substantiate their treatments, they may be predators. A non-predatory practitioner will be very upfront about a novel combination of treatments being completely experimental and will discuss the benefits and risks of trying the new treatment, openly. If they don't present risks, that's another red flag.
   3. The practitioner isn’t treating the cost of the treatment as a potential risk to client wellbeing. A high quality practitioner whose services will not be covered by your insurance should discuss with an estimated total cost of treatment with clients, what that expense means to their budget, and how to reduce its impact. They should also be open to discussing alternative treatment plans that may be less expensive.
   4. The treatment is characterized as a magical unicorn without a reasonable failure rate. Even strong evidence-based treatments for known afflictions can fail. Non-predatory practitioners will set reasonable expectations for the treatment and most treatments shouldn't be promised to be anywhere near 100% effective, especially for chronic mystery illnesses. A realistic "high" cure rate could be 60-80% for complicated cases of anything. Even prolonged exposure therapy for acute PTSD (gold standard treatment for wartime trauma) is somewhere around 90% effective. If a practitioner is making unrealistic promises in exchange for payment, that’s a sign something may be amiss.
   5. Their approach is non-systematic/non-scientific. Any practitioner who suggests changing multiple variables at once when addressing a chronic mystery illness should viewed skeptically. This isn't to say that if several well understood issues emerge in an initial examination, that they can't be treated simultaneously (I think a Dr. might be able to begin treating high blood pressure, thyroid problems, high cholesterol, and diabetes all at once if they were all diagnosed on the same day. I don't know for sure, but this wouldn't raise my personal alarm.). I become concerned when a patient walks out of a practitioner's office with 20 different supplements, all purchased from the practitioner's office (profit to the practitioner), with no particular plan of how to monitor how each intervention influences the patient's overall condition. Most of the alternative practitioners I collaborate with will change only a couple of variables each visit, using the scientific method (observe/examine, identify a question, form a hypothesis, conduct an experiment, collect and analyze data, draw a conclusion, and repeat) and peer-reviewed evidence to identify next steps.

You can use all of these “warning signs” to help your client maintain awareness of their investments in care, advocate for themselves, get second opinions, increase likelihood of a methodical approach, increase their own understanding of their health, and advocate for best practices WITHOUT giving any medical advice or getting yourself into trouble for practicing outside your scope.

Finally, expect to use your motivational interviewing skills intensely and for a long time. Especially for clients who are spending a majority of their time, energy, and money on resolving their illness, it can take a long time for them to recapture other valued activities in their lives. Many have developed the idea on their own and others have been told by practitioners that the ONLY way to get better is to do more and abandon other valued things in life to focus on their health, often with the (perhaps false) promise that they will get better and do those valued things again, someday. Unfortunately, some chronic diseases will never get better and in my experience, it’s best to help clients develop a sustainable approach to managing symptoms or treating the disease. Your client’s PCP can be the ultimate “safety monitor” for determining how much a client can abandon disease management activities in exchange for engagement in other valued parts of their lives. My recommendation is to help clients do as much as is medically safe for them to do in terms of engaging in things other than “being sick.” Isn’t that what we would do to help our clients with chronic or acute “known diseases” to do?