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Ethics Dispatch

"The object of philosophy is the logical clarification of thoughts. Philosophy is not a theory but an activity."

- *Ludwig Wittgenstein*

Hot Topic: The Ethics of Non-Adherence

Non-adherence is common among those suffering from chronic illness. A recent article by Fred Kleinsinger (2018) notes that medication nonadherence impacts "40% to 50% of patients who are prescribed medications for management of chronic conditions such as diabetes or hypertension. This nonadherence to prescribed treatment is thought to cause at least 100,000 preventable deaths and $100 billion in preventable medical costs per year."

The article lists several reasons for patient non-adherence, many of which are categorized as patient-related. They include a general lack of motivation, denial, drug/alcohol abuse, depression and cognitive impairment.

On the face of it, these reasons make sense. Intuitively, if depression can affect how a person functions at an individual level, then, by fiat, this could affect whether person adheres to medication. A meta-analysis published in the Journal of Internal Medicine notes that poor medication adherence for chronic illnesses is significantly impacted by depression.

It's important to note that non-adherence goes beyond *medication* non-adherence. Non-adherence during the COVID-19 pandemic, for instance, has had a significant impact on public health. The Center for Disease Control has urged Americans, at various stages of the pandemic, to socially distance, wear masks and get vaccinated. Recently, the CDC has offered county-specific mandates given the recent decline in cases from the Omicron surge. The general idea here is that these specific measures will frustrate the spread of Sars-CoV-2, severe disease from COVID-19, or even death. As the past few months have evidenced, the overwhelming majority of those hospitalized for COVID-19 are unvaccinated, and this is more than a year after the vaccine rollout. Non-adherence, in these cases, has downstream effects related to public health: decline in healthcare employment, burnout among healthcare workers, and depletion of hospital resources.

Whether it's medication for chronic illness or preventative measures during the COVID-19 pandemic, all cases of non-adherence invite the question: What *exactly* are we licensed to infer from non-adherence? Should we assume, say, that the depletion of monoclonal antibodies or ventilators are due to individuals *who simply don't want to get vaccinated?* Are heart, kidney, or liver complications that result from medication non-adherence due to individuals *who simply do*

not wish to take their medication? Should we assume that a patient labeled as "nonadherent" has no desire to participate in their care?

Case Study

A 45-year-old female-identifying patient is brought to the ER for suspected cardiac symptoms. Her name is Peggy. Peggy is accompanied by her son Michael, who informs the attending physician that his mother has been complaining of chest pain.

After learning more about her medical history, the physician suspects her symptoms are indeed cardiovascular related and also untreated hypertension. A brief phone call with Peggy's primary care physician confirms this; her PCP notes that Peggy was prescribed blood pressure medication several years ago, which she has not been taking despite her family's constant pleas.

After a cardiology consultant examines the patient and runs some tests, it is determined that the patient has sustained heart damage, which is correlated to medication nonadherence for hypertension. The cardiologist assures Peggy that the cardiovascular issues are still treatable. However, to avoid ER readmissions in the future, the patient is urged to make significant lifestyle changes and start taking her hypertension medication.

The attending physician subsequently meets with Peggy and her son to discuss this diagnosis, prognosis, and the proposed treatment plan. Peggy nods her head enthusiastically in agreement and promises to start taking her prescribed medications. Peggy says she wants "to get better," that she wants "to live a long, healthy life for my children and grandchildren." Michael doubts, however, that his mother will make these changes. He says, "Mom, you've made these promises in the past and yet we're here in the ER. Your family loves you so much, but how can we be sure you're telling us the truth this time?"

The physician is concerned. Peggy's history of nonadherence and Michael's plea signal a potentially deeper issue. The attending physician wants to provide the best medical care possible, to see his patients recover and remain well. But he tells a colleague that he isn't convinced that this patient "gets it." "She knows what she needs to do to get better, yet there seems to be no desire on her part to get better. It's a shame that we have to send these noncompliant patients home only to see them right back here again a few weeks later."

Bioethics in the News

- The Need for Praxis in Combatting the Race Idea in Bioethics
- Pope Francis' March prayer intention: For Christians facing new bioethical challenges
- World Trade Center Responders at High Risk for Blood Cancer
- Comments on High Functioning Depression

Ethical Musings: Voluntary vs. Involuntary Non-Adherence

In a recently published article, "Voluntary and Involuntary Nonadherence: Terminology for Labeling Patient Participation," the Center's own Ryan Pferdehirt issues a distinction between types of patient non-adherence. Before explaining the distinction, it may be necessary to offer a definition of the term "adherence." The World Health Organization defines adherence as "the extent to which a person's behavior—taking medication, following a diet, and/or executing lifestyle changes—corresponds with the agreed recommendations of a health care provider."

Given this definition, we might define *non*-adherence as low correspondence between a person's behavior and the treatment recommendations of a healthcare provider.

Voluntary non-adherence captures cases where patients choose not to comply with such recommendations. For instance, if a patient is diagnosed with diabetes and is given a treatment plan and daily medication for their diabetes, but subsequently chooses not to follow through with the plan because they do not wish to, then this would count as an instance of voluntary non-adherence. There are cases, however, where a patient fails to adhere, but for reasons "beyond their control":

> Patients of lower socioeconomic status are far more likely to not own a car, have inadequate means of transportation, not have schedule flexibility to make appointments, and have restrictions due to domestic responsibilities such as child or elder care. This may result in those patients more often being labeled as nonadherent.

Let's imagine that a particular person's prescribed treatment regimen requires regular visits to the outpatient clinic. Let's further suppose that they do not own a car or have any reliable means of transportation. As a result, the patient misses several appointments. This could seem to imply that they don't want treatment. However, it may be that their health actually is a high priority and that missed appointments imply only that the patient lacks adequate transportation and needs assistance in that regard also. Cases of involuntary adherence are those in which patients *want* to adhere to treatment but are unable to do so due to a lack of resources (or some other external factors). These cases complicate the assumption that a "non-adherent" patient does not want care.

Already, this distinction opens a world of possibilities when thinking about patients, how they are labeled, and how we provide care. There are always a wide range of factors that determine health outcomes, some of which a clinician may be unaware. When reflecting, for example, on unvaccinated patients during recent pandemic surges, and the impact this has had on our health systems, it is tempting but inaccurate to assume that *every* unvaccinated patient *does not wish* to get vaccinated.

Many are indeed unvaccinated by choice, while at least some unvaccinated persons remain so for reasons other than hesitancy and refusal. As Ryan Pferdehirt points out, some individuals have been unable to get vaccinated due to a lack of resources. They may lack internet or a computer or be unable to read. They might not have transportation to and from the vaccination

site or availability during scheduled vaccination times. Many of us take these resources for granted. In short, vaccine non-adherence does not necessarily indicate that a person doesn't want to be vaccinated. The same could be true regarding many other situations of healthcare non-adherence. It might be involuntary.

Are we justified, then, in assuming that Peggy (in the case above) has "no desire to get better"? Is the ER physician correct in assuming that Peggy is caught in a pattern wherein she promises to engage in her own self-care, and yet intentionally chooses not to? Is this *voluntary* non-adherence?

This is where Pferdehirt's distinction can be put to work. Recognizing the distinction between situations of voluntary and involuntary nonadherence forces us to pause and ultimately suspend judgment in the absence of further evidence. It may be the case that Peggy is on a very tight budget, barely able to make ends meet. Perhaps her finances are so incredibly strained that she simply cannot afford her medication, much less significant life-style changes recommended by Cardiology. For instance, what if this involves a change in her eating habits and thus ready access to nutritious food? Food deserts, with limited access to a supermarket, play a substantive role in poor health outcomes.

Some patients like Peggy might be suffering minor cognitive impairment that limits ability to follow through as directed. There might be some short-term memory loss. Indeed, there are a multitude of reasons why some patients don't do as they are told or as they promise, reasons other than willful nonadherence to medical recommendations.

So too for Peggy. Her medical team should pause before discharge so as to pin down whether her history of non-adherence is voluntary as presumed, or perhaps involuntary instead. Doing this could mean the difference between a good outcome or merely sending the patient home only to see her "right back here again a few weeks later."