

## **Fathoming the Mental Life of Those with Medical Illness:**

Why understanding the thoughts of patients with chronic disease is critically important

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There are fast suicides and slow ones. The slow ones are less dramatic, more garden variety, but feel nonetheless wrong. She's non-adherent, a doctor will say, summing up in one term a constellation of complexity, a history of breakdown in the doctor-patient relationship, a seemingly illogical equation: diagnosis plus known treatment does not equal improved outcome.

Ms. P was one of them, a preventable death, a young person lost in one of the best hospitals in America to an infection we have medicine for and know how to treat. To me, she was a mystery from the very beginning.

Like me, she was in her 30s and a mother of two. Like me, I thought, she was mostly healthy, and should be out of the intensive care unit quickly. She was breathing rapidly through a positive pressure facemask when I first walked into her room. Her thin chest heaved with the effort. She could barely get out a few words in response to my questions: Why don't you want to be intubated? What are you worried about?

As a fourth year medical student going into psychiatry, I prided myself on my talking skills, my ability to understand where patients were coming from and to help them understand where I, and by extension, the medical establishment, was coming from. Ms. P frustrated my one talent.

She had pneumonia and a collapsed lung, and the critical care team, feeling that she would be unable to sustain breathing on her own for very long, had requested permission for an elective intubation. She did not want to go to sleep and wake up two days later, she said. She did not believe anyone's assertion that this would not happen, that we would sedate her as little as possible. Frankly, based on my observations of intubations, I thought she had a point.

However, that point might cost her life. She agreed to have an emergency intubation when it came to that: a procedure that would be less controlled, more rushed, less safe. But before then, she would not cede control. I had been an English teacher before going to medical school, and she reminded me of one of my hard-nut-to-crack high school students, with her stubborn insistence on a course of action that seemed to me counter productive. I admired her strong will and wondered how this insistence in the very face of death might have served her in the past. I also wondered about her lack of trust, where she had learned to make her own decisions, against the advice of experts.

Surprisingly, she held out for several days, longer than anyone expected. Once she tired out, and was intubated, it was a relief for the medical team. Now we could fully treat her, making decisions each day about how much oxygen she should get, how many breaths per minute. We got an infectious disease consult: she had HIV and was known by her primary care doctors not to be taking her antiretrovirals. We began testing and treating her for every infection we could think of, but particularly for pneumocystis jiroveci. There was good research on improving outcomes by using anti-HIV drugs at the same time, and we followed it. I thought it was a matter of two weeks, maybe

three, before she would be well enough to resume our conversation and move to a general medical floor.

The infectious disease attending warned me. This can kill people, she told me. I've had patients die of PCP. I did not believe her. There were many patients around me in the ICU who had many strikes against them: bad livers, bad kidneys, bad hearts, advanced age, and some of them would get better. I found it unlikely that a thirty-some mother of two who had been in fine health before this, but simply not taking her pills, would not have a second chance to thank god for a close call and move forward, wiser for the experience.

I kept thinking that sometime over the month that Ms. P was in the hospital, I would have a chance to talk with her and to understand what she believed about her disease, why she did not take her pills, what it meant to her to take them or not take them, what some of her past experiences had been that brought her to this point, and what her hopes were for the future. I was wrong.

There were small dramas along the way: Ms. P was extubated and then reintubated. Her tachycardia improved, but then it got worse. She became less acidotic, but then more. Her body made a slow march away from life that we could not halt.

Her grandmother returned to the floor the day after she died needing a death note. That was perhaps the only service I was actually able to provide. I called her, months later, to try to understand more about what had happened. Ms. E was a gracious soul, and spoke proudly of the funeral turnout. She was no stranger to loss. She had raised Ms. P from a baby, when her mother died, of what causes Ms. E wasn't sure. Her father, Ms. E's son, had been found dead in an abandoned house, killed while he was still young.

“Was Ms. P depressed, do you know?”

Ms. E couldn't say. She had seen pill boxes in the home where Ms. P lived with her two kids. They seemed too full. Also, Ms. P loved the church. That she knew.

An autopsy was done. I had been told they are often revealing, sometimes offering a cause of death unknown to the medical team. There were no surprises in this case. She died of pneumonia that killed her because she had HIV and would not take medicine for it.

How many, like Ms. P, die too soon, before they have raised their kids, or accomplished something important to them, or said goodbye? Because they refuse, for mysterious reasons, to adhere to a treatment that is available to them?

Those who question the importance of investigating the mental life of those battling medical illness should spend a month in the ICU. There we pour thousands of dollars and hundreds of hours of attention into saving many who have made unhealthy choices that put their lives in peril. Often, our efforts are too much too late.

Currently, psychiatry and the medical establishment focus mostly on mental illness, a state of dysfunction that requires a serious breakdown in everyday life in order to receive attention. Psychiatric consults in the hospital are requested for those patients showing an extreme of unhealthy behavior we call suicidality, when someone is immanently threatening their own life, but

not for those with everyday unhealthy behavior or for those struggling with the challenges of coping with chronic disease and the drastic life changes illness often requires.

Would it be absurd for a mental health evaluation to become standard of care for certain types of patients in the hospital: those with predictable chronic disease who will need to adhere to specific regimens to prevent early disability and death and those with illnesses that are exacerbated by unhealthy behaviors resulting in frequent admissions? Too costly, many will say. Yet, a recent study by doctors at Yale found cost savings through decreased length of stay when a psychiatrist embedded on a medical team was involved in the care of all patients admitted to their unit.<sup>1</sup> The study focused on removing barriers to discharge during a single admission. Imagine if we could remove barriers to healthy choices over the long term.

Would it also be absurd for mental health professionals to be embedded in outpatient clinics so that both patients and staff see them as a readily accessible and integral part of wellness care, rather than a last resort for acute or intractable cases? Current practice is to call in the psychiatrist when the medical team is frustrated with patients who are not getting better as expected, to see if there is some other diagnosis, such as malingering or somatization. Patients feel this frustration and fear, sometimes rightfully so, that their specialists no longer trust or want to care for them. Thus the foundation is poorly laid for a therapeutic relationship with the presenting psychiatrist who appears as a punishment for poor health. For those with chronic medical illness, we must realize that mental well being itself is crucial to managing disease long term and stop reserving mental health therapies for those with select mental illness diagnoses.

Finally, is it absurd to invest in research on how to promote mental well being and healthy choices for those with chronic debilitating medical illness? Similar to the two-hit-hypothesis in cancer, in which a first genetic insult becomes lethal only after a second insult multiplies its effects, run-of-the-mill poor choices in the context of severe disease equal surprisingly devastating consequences. We know the results of no intervention in these cases: increased medical costs and worse outcomes, often death after a futile stay in an ICU. Despite four decades of research on adherence, we still do not understand why people make unhealthy decisions for themselves or how we can best intervene. Much work remains to be done to understand the mental life of those for whom relatively small decisions, such as not taking a pill, will have fatal results.

It is true that investing in mental health will never make sense economically without taking future cost savings into account, the same way paying for a screening colonoscopy makes no sense, unless you take into account the cost of cancer ten years later.

What would have happened if we had invested resources and time in exploring and supporting the mental life of Ms. P well before she got so sick one day that her lung collapsed and she got a pneumonia that she could not recover from, despite the best available medical treatment? Her doctors knew and had warned her that she was risking death. They had arranged transportation to clinic, called to remind her of appointments, filled pill boxes, had her meet with a pharmacist to work out the regimen that was best for her, offered to deliver pills through directly observed therapy. Tragically, none of that worked and she remained stubborn to the very end, for reasons we will never know. Can we really do no more? Shouldn't we at least wonder?

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<sup>1</sup> Desan, PH et al: Proactive psychiatric consultation services reduce length of stay for admissions to an inpatient medical team. *Psychosomatics* 2011 Nov-Dec; 52(6):513-20.