Chapter 8

The Need for Therapeutic Context: Lived Experience with Psychotropic Medications

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Introduction

In many settings, the act of prescribing psychotropic medications has become synonymous with practicing psychiatry, with brief "med check" visits representing a standard model for psychiatric treatment. The less visible tasks performed by the psychiatrists may be overlooked in the reductionist framing of the role as mere "psychiatric prescribers." Centralizing the role of prescribing – the most concrete and measurable task in a treatment frame that consists of mostly intangible elements – ignores the central feature of any patient–physician dynamic: the therapeutic relationship. This reduction of psychiatric care to a singular transactional element not only invalidates what is core to a successful treatment, it also makes the relationship more vulnerable: a transactional relationship can be easily subverted.

Although less measurable, it is in the relationship between the patient and the psychiatrist where healing resides. For this relationship to be successful it must be able to accommodate the real and perceived ability to check in over time, despite cost and despite a perceived maintenance of, nor increase in, wellness. Without this, pitfalls abound for both patient and physician with psychiatrists feeling pressured to "perform care" via prescribing meds or ordering concrete interventions – or even worse, feeling compelled to collude with patients around treatments that are unlikely to help and may even harm. For patients, this constant looming of intervention can result in hesitancy to be forthcoming about their symptoms and response to treatment.

This chapter is composed of a series of impressionistic patient narratives – each one representing an amalgam of real patient stories – that highlight the ways in which the therapeutic relationship and acts of prescribing can bidirectionally both strengthen and undermine each other, and how psychiatrists can fortify the long-term "community of two" that is essential in giving patients with chronic mental illness the ability to survive and thrive under their doctor's care.

Case #1

Mariam is a woman who, at the age of 22, was hospitalized several times in fairly rapid succession for paranoia and delusional thinking. To each hospitalization she was brought by force by police and as she was hesitant to take medications she was ultimately compelled to do so by a court order. Her hospitalizations were traumatic and resulted in her fearing that if she did not present as "well enough" to her outpatient psychiatrist, Dr. Jones, she might be recommitted. From her third hospitalization she was discharged on olanzapine and although it was helpful in reducing her delusions, organizing her thoughts, and enabling her to regulate her sleep, her weight ballooned. Of her regimen she said, "The diagnosis of

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schizophrenia was shameful enough, being fat on top of it was unbearable." But she wanted more than anything to avoid rehospitalization. She had overheard the nurses on the inpatient unit describing other patients as "frequent fliers" who always stopped their meds after discharge. She could sense their contempt for those patients, and didn't want to be on the receiving end of it.

Over several years of outpatient treatment Mariam was trialed on nine different antipsychotics, each one effective at keeping her psychosis at bay, but each also provoking new side effects – sedation, acute dystonia, akathisia, and a bowel obstruction, to name just a few. Dr. Jones once commented that the flip side of being so susceptible to side effects was that she seemed to also be susceptible to medication benefits, which to Mariam was "only part consolation." The continuous trials were exhausting and she worried about running out of options. She worried also about Dr. Jones running out of patience. Sometimes she sensed a tension in Dr. Jones, like she feared running out of options too. They had many conversations about needing to make a cost benefit analysis, to choose "the lesser of the evils," but that was easier said than done.

After Mariam suffered an intolerable bout of akathisia from aripiprazole that had her contemplating suicide for the first time in her life, Dr. Jones suggested a retrial of olanzapine. As Mariam put it, "I didn't actually tell her about the akathisia right away, I wanted to just wait for it to abate – afraid that she would give up on me if yet another medication failed." But when she found herself picturing the jump to the street from her sixth-floor apartment window she knew she had to speak up. Going back to her original medication regimen she felt like an utter failure, and she feared that Dr. Jones felt like a failure too. Deciding that it was the best option at the time, though, she was restarted on olanzapine which she continues to take today.

Case #2

At 34 years old and after a decade and a half of psychiatric treatment, Horace is facing a reckoning: "It's hard to imagine that we just had it wrong for all of these years," he says about his time in treatment. Over the years, he had trialed numerous medications and interventions for depression including transcranial magnetic stimulation (TMS) and electroconvulsive therapy (ECT). "To think that we were chasing a cure that didn't exist, or perhaps even worse, chasing a cure for the wrong ailment, is just shocking." But in fact he believed it was the latter that was likely transpired. Horace began seeing a psychiatrist in his teenage years after his parents discovered that he had been cutting his thighs with a razor. After confronting him about his behavior, they learned that he had been thinking about suicide too, going so far as to hold a belt around his neck on a couple of occasions. Frightened, his parents sought recommendations for the "best psychiatrist in the county" who also, as it happened, turned out to be the most expensive. Even though it was a struggle to afford, his parents wanted him to see the most expensive doctor because in their minds it meant he must be the best.

Horace doesn't recall if he and his psychiatrist, Dr. Goodman, ever explicitly discussed his diagnosis but he assumed that they agreed: "depression." Horace underwent myriad medication trials of various antidepressants and augmentation strategies. "Dr. Goodman was like a wizard," he says, "never stumped by my quick response to a medication only to 'poop out' after a few weeks or months." When his thoughts about suicide or his cutting worsened, Dr. Goodman always had a plan for something else he could try. Even when

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medication failed, he had ideas: TMS, ECT, ketamine. But just like with all previous interventions, after short-lived success, Horace inevitably found himself back to square one with mood problems and suicidal thinking. Then his psychiatrist died.

"I completely fell apart when Dr. Goodman died," Horace reflected. "He had been there for me for so many years – always had a solution when I felt stuck. How would I find another doctor of his caliber?" Horace had no idea how to find a new doctor. He had been told by his parents that the "really good psychiatrists" did not take insurance, and so he could not get a referral through his insurance provider. He had no idea how to find someone. Devastated and lost, he presented to a local community mental health clinic where he was seen by a new psychiatrist for evaluation. After a multisession evaluation and review of his records, she offered her diagnosis: borderline personality disorder (BPD).

"I was shocked, and rather insulted, if I am to be honest," Horace recalls. "A renowned psychiatrist had been treating me for treatment-resistant depression for years and this clinic doctor thinks she knows better?" His husband urged him to consider hearing Dr. Schwartz out, pointing out that in spite of many years of treatment he was still struggling with many of the same problems. Maybe a fresh perspective was what was needed. What clinched it for him was a symptom checklist Dr. Schwartz asked to review with him. Almost every single item on her list seemed to describe his experience perfectly, like the list had been written for him. Dr. Schwartz explained that these were the criteria for BPD and that she thought it best explained many of his struggles, including his continuous cutting and thoughts about suicide.

Horace has been engaged in individual and group dialectical behavioral therapy and in treatment with Dr. Schwartz for the past 18 months. He is on an antidepressant to treat the major depressive disorder Dr. Schwartz thinks is comorbid with his BPD, and he has been struck by the fact that in their 18 months together they have made few medication adjustments. They spend less time discussing medication and more time talking about his illness and his life. "Sometimes I forget that I am at the doctor because it feels more like a tutoring session," he says. "Dr. Schwartz will draw diagrams of the brain and once she even showed me a few PowerPoint slides on her computer! I feel like more than anything I am learning how my mind works. And it is helping me cope."

Case #3

Moses traces the origins of his psychiatric problems to a night during his junior year of college where he "made the terrible mistake of trying cocaine." A student at a premier engineering school with a bright future ahead of him, he found himself quickly and dangerously enamored of this newfound "productivity serum." But it was not long before "the demons arrived" and he became convinced that the CIA had bugged his home and that agents were tracking his every move. After hacking through the walls and pulling up the floorboards in his apartment in search of a bug, Moses was hospitalized for nine days and treated with a combination of a mood stabilizer and antipsychotic – medications he recalls were started when he was still in the emergency department awaiting transfer to the psychiatric hospital.

Highly motivated by his desire to pursue a career in the sciences and fearful of "losing my mind again," Moses continued taking his medication and followed up regularly at the student mental health clinic. He saw a variety of psychiatrists over the years, at least a few of

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whom suggested that his medications might not be necessary for the long term. But being a highly risk-averse person, he felt staying on medications was the safest course of action.

Moses' mindset shifted when he moved to a new city for graduate school and his new psychiatrist, after conducting a multisession evaluation, wondered if the potential risks of long-term medication use might exceed their benefit. Moses reflected, "The idea of tapering medication was not new to me – but her way of thinking about it was: *it might be worthwhile to consider the risks as well as benefits of staying on medications*." To his mind, there was risk associated with cessation of treatment, but he had not considered the reality that there were risks associated with continuing treatment. "I had gained weight on olanzapine and had a tremor from lithium – but held up against the seriousness of psychosis – of literally destroying my apartment, terrifying my friends, and being locked on a psych ward – those seemed but minor inconveniences."

Over the course of two full years Moses and his psychiatrist, Dr. Shankar, engaged in risk benefit analysis followed by careful planning of his taper. "I often wondered if I was overthinking it, if I should just rip off the Band-Aid and hope for the best." But Dr. Shankar never pressured or rushed him. After completing his qualifying exams, Moses and Dr. Shankar commenced a "painstakingly slow taper."

Now off medications entirely for 18 months, without any psychotic symptoms, Moses remains ambivalent about medication. "I want to say that I am thrilled to be off meds, that I feel like my psychotic episode is squarely in my past, but honestly, it's complicated." He is married with a young child and has a career he enjoys. Yet uncertainty remains about his psychiatric trajectory. With each day that passes he feels the likelihood of psychosis re-emerging diminish, yet it remains a possibility still. At times he misses the medications and the security he felt being on them: "it's as though a layer of protection has been removed that previously had shielded me." Moses continues to see Dr. Shankar, with whom he feels comfortable discussing these fears. His friends and family question the ongoing relationship because she is no longer prescribing meds. They question what he is paying for. "I try to help them understand the value of being able to check in and the knowledge that if things start to sour, she is right there to help me turn it around. I think that's priceless."

Case #4

Melanie is a 55-year-old woman who has been in treatment for posttraumatic stress disorder (PTSD), depression and anxiety for decades yet regards her last 10–15 years in care as "one continuous exercise in frustration." With years of treatment under her belt, Melanie has a good sense of what helps (her diazepam) and what does not (everything else). "This wasn't a problem until this younger crop of psychiatrists came around thinking that everyone is a junkie." During her initial years in treatment, Melanie's psychiatrist treated her anxiety and PTSD with alprazolam, then diazepam, with doses escalating over time when her symptoms worsened. Melanie was referred to psychotherapy, which her psychiatrist felt strongly was necessary for her recovery, but Melanie did not take to the idea of "sitting around and telling a perfect stranger about my problems." Medications were an intervention that worked well enough.

However, when Melanie's psychiatrist retired, the problems began. Each new doctor she visited felt her medication regimen was not one that they could continue without adjustment. They all agreed to treat Melanie with the understanding that tapering her benzodiazepines would be part of the plan. This approach enraged her. "No one cares about the

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crippling anxiety that makes it impossible for me to leave my house most days, nor the nightmares I have almost every night that leave me feeling exhausted in the morning, nor the depression that causes me to think about suicide. All they care about is stopping my diazepam!" Melanie thought about purchasing benzodiazepines on the street, or from a "pill mill," but decided against it, wanting medications prescribed by a "legitimate doctor for my legitimate problem."

After falling twice in her home and breaking her arm and then her hip, Melanie's psychiatrist insisted on beginning to taper her diazepam. Although she and Melanie had only met twice, she was highly concerned given Melanie's use of alcohol and narcotics for chronic neck pain in addition to the diazepam. Melanie was enraged. "If I am willing to assume the risks, why do they still insist on stopping it?" To add insult to injury, Dr. Garzon suggested that buprenorphine might be a good option to consider instead of oxycontin. Melanie was shocked. "She thought I was a drug addict! Why? Because diazepam helps me? Because my urine screen had cocaine and heroin in it? I think psychiatrists need better education about drug use. Not everyone using drugs is an addict. Do doctors not ever drink alcohol? Please!"

Melanie pleaded with Dr. Garzon to consider not only *not tapering* the diazepam, but instead *increasing* the dose because the conversations about tapering had felt so destabilizing. Dr. Garzon acknowledged the difficulty of their undertaking as well as the way the newness of their relationship made it difficult to garner the trust needed for the plan. But still she emphasized, she had concerns about the safety of this regimen and felt they needed to start making adjustments without delay. Dr. Garzon offered a hospitalization for detox as an alternative to a slow outpatient taper. In response, Melanie had stormed out of the office. Later that day she snorted heroin with her husband to help settle her nerves. "Can you believe I have to use drugs because my doctor took away my medication?" She asked. "This could kill me." Melanie is planning to discuss her upset with Dr. Garzon at their upcoming appointment next week.

Case #5

Thomas is a young man who, in his mid-20s, began to undergo behavior and personality changes: first he stopped bathing and laundering his clothes and became hesitant to leave home. At some point his parents noticed an offensive odor emanating from his room and entered to find containers of feces stacked along the wall. Lacking full memory of that time, Thomas does recall being put on a plane to Ghana – where his parents thought he should go to get better. Wary of the psychiatric system in the United States, Thomas' parents arranged for him to live with cousins who had a large amount of property outside of Salaga. They thought the fresh air and quiet would help him get back to himself.

Entering the plane, Thomas was bombarded with sounds and scents that felt overwhelming. He pressed the button for help, but when the flight attendant arrived, he couldn't find the words to explain what was wrong. "I was jumbled up, I just sat there staring at her." His brother, who was accompanying him on the trip, attempted to intervene, which only worsened the sensory overload. Thomas jumped up and began pacing the aisles, shouting and clutching his head. He was escorted off the plane and then to a nearby hospital for evaluation. The psychiatrist recommended hospitalization and treatment for psychosis, but Thomas' parents declined, choosing instead to take him home so that they could focus on helping him eat well, get daily exercise, and maintain a prayer schedule.

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Over the course of the following six months Thomas was brought to the emergency department four times, always in response to 911 calls about bizarre behavior such as drinking directly from a puddle in the street or walking against traffic on a busy road. Each time he was discharged after evaluation, per his parents' request. One psychiatrist after another pleaded with them to consider hospitalization, or at least referral to outpatient treatment, but they declined. Then, on a family vacation in a nearby state, after being found rummaging through the hotel rooms of other guests, Thomas was once again taken to the hospital. This time he was admitted and treated.

With many fits and starts, including a few near-hospitalizations after self-discontinuing medications, he eventually found a blend of medications that are both beneficial and tolerable. He lives in a group home and works part-time stocking shelves for a local Big Box retailer. He enjoys social activities at a local recovery center where programming for people with psychiatric illness is available. Thomas' parents remain wary of psychiatric treatment but are pleased with how well he is doing. They have even met his psychiatrist, Dr. Callahan, a handful of times to learn more about her approach to treatment.

Thomas looks back on his visits to the emergency room and wonders how different life may have been for him if he had been "forced" to receive help earlier. "I lost a full year of my life being so sick," he reflects, "and I was allowed to live like a non-human." Sometimes he dreams about eating from public trashcans and sleeping outdoors – waking up bathed in fear and humiliation. "No one should be allowed to eat garbage or sleep in the street." But Thomas also wonders if earlier treatment would have been futile. "I mean, I kept stopping medications because I didn't like the way they felt," he says, referring to his post-hospitalization course. "And I didn't think I really needed them either." He notes that it took months of work with Dr. Callahan before he became willing to take medication in an ongoing way. At first, he worried that she would not want to treat him if he were not willing to take medications. Her response to his concerns: "Talking about medication is just as important as actually prescribing or taking them," she had said. From time to time, he still wonders if medication is truly needed, something he continues to discuss with his doctor.

Conclusion

Medications are a critical part of psychiatric treatment and, in many cases, essential to achieving recovery. For numerous patients, the power of psychotropic medicine has paved the path to wellness. These stories are meant to illustrate that the context in which medications are prescribed is as important as the medicines themselves. That is, although treatment with psychotropic medication can be necessary, it alone is not sufficient.

Uncertainty abounds in medicine and is arguably most pronounced in psychiatry. It is woven through every aspect – from diagnostic formulation to medication mechanism and effectiveness to prognosis and illness course. With uncertainty comes risk. Risks include incorrect or evolving diagnosis, medication ineffectiveness, or side effects – all of which can necessitate a change in treatment course. It is the therapeutic relationship that provides a fail-safe against these risks. In Cases 1 and 2, course correction with medication was successfully executed because the physician–patient relationship was sound, whereas Case 4 underscores the added layers of complexity that exist when a treatment change is needed in a relationship that has not yet been solidified.

A consistent theme in these stories was how essential to recovery a long-term and trusting relationship with a psychiatrist could be. Patients appreciated the benefit in being

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able to check in, to discuss their concerns, and to share their experiences as much as, or even more than, they did in being prescribed medication.

The benefits of psychotropic medication are numerous and can be lifesaving, yet the success of the medication interventions is intimately tied to the strength of the physician–patient relationship. Success of a medicinal regimen requires a sound therapeutic context as a precondition, and the absence of such a precondition can be devastating.

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