

## Users and Refusers

*Basically, they just send you out, and they're like, "Well, looks dismal. Looks gray. They can either recover and figure out how to fix this on their own, or they can just probably off themselves."*

—AMY, AT STARBUCKS, WEEK 12

Pedro was an easygoing Hispanic youth with kind, amber eyes who quickly put people at ease. He was the youngest of six boys followed by three more sisters. Pedro said he had moved to the United States when he was six, but that his parents were Tejanos—which he described as the Mexicans who lived in Texas before it became part of the United States.

Though intelligent and dynamic, Pedro had always struggled to belong. In his first interview, he explained: “I was always tired. I didn’t want to go to school anymore. It was just a bad time. And people tried to pick on me—bullying, harassment, racial profiling, all of that. I left high school in the eleventh grade and decided that was it. I was already 18. I went and got my home-school diploma.”

He tried starting a career without a college degree, but didn’t get very far, so he went to community college to start working toward a four-year degree. When my team first met up with him at Shady Elms, he was on mandatory leave from a four-year college that he had transferred to that year.

Pedro said his father served in Vietnam and then later worked for the FBI to help take down the “Cocaine Cowboys,” which is also the title of a crime documentary released in 2006 about the police taking out a drug-trafficking ring in Miami in the 1980s.<sup>1</sup> His father had a posttraumatic stress disorder (PTSD) diagnosis from these experiences, Pedro said, adding that he, too, had been diagnosed with PTSD when he was 6 years old. He had also been diagnosed with attention deficit hyperactivity disorder (ADHD).

It is hard to know which parts of Pedro’s story are true, but clearly the world of drug traffickers and the potential for violent death had become a sticky place in his mind—a theme that preoccupied him. Pedro lived in a social context where drug trafficking and people being murdered for their involvement was very real. The US

“war on drugs” started in 1971 when Richard Nixon declared “drug abuse,” or the use of illegal narcotics, to be “public enemy number one.”<sup>2</sup> The “war” began with strict laws and harsh penalties that ultimately came down hardest on small-time dealers or people experiencing substance use disorders in the United States, and the policy approach has been criticized for its long-term negative consequences for American communities of color.<sup>3</sup> In countries that were supplying cocaine and heroin to the United States, the war on drugs meant destroying coca and poppy plants and supplying local security forces with arms to take on organized drug lords.<sup>4</sup> These activities seriously impacted countries in Central and Latin America and the Caribbean where organized crime in the form of “cartels” battled with those trying to stop drug trafficking to North America.

The negative effects of the US-backed War on Drugs continue to be seen today.<sup>5</sup> In 2018, Latin America was home to 8 percent of the world’s population but had over one-third of its total homicides. While drug trafficking is not entirely to blame, places like El Salvador, where two rival gangs have declared a truce still in effect at this writing, have seen a sharp decline in the murder rate.<sup>6</sup> While some white residents have also been affected by drug-related violence, Latinx US residents are more likely to experience drug war–related trauma than white residents.<sup>7</sup>

It was in this social context that Pedro developed the understanding that he was being stalked by Central American gang members in the guise of women who drank alcohol. He called them the “Liquor Ladies.” He thought the Liquor Ladies were trying to murder him for his connections to his father. Pedro knew who they were and what they looked like, but no one else he knew personally had seen them. Pedro saw them all the time before his hospitalization. He saw them when he went to clubs with his fraternity brothers. They left him secret messages on Facebook that vanished after he read them. They appeared on his college campus, too—in the library and in his classroom during exams. They distracted him so much that he failed his classes.

Pedro’s college was a few hours away from home, so his family did not realize something was seriously wrong until he began posting comments about these Liquor Ladies on Facebook. He posted pictures of random women consuming alcohol and demanded they leave him alone or he would hurt them. Concerned, his family obtained a warrant from the local magistrate while he was home during a school break, which enabled the police to escort Pedro to Shady Elms for further evaluation without his permission.

Once there, he reported that he was forced to take a medication that made it difficult to breathe. He explained: “The prescriptions . . . I had a hard time breathing so I stopped taking them and I was able to breathe better. I just had a hard time sleeping at night.”

Pedro was also dealing with other stressors. Prior to his break, he had been placed on a three-semester forced leave from college for poor performance. Even

so, his student loans were still due because he had been dismissed after the deadline for a refund. He needed to work to pay the loans, but the only jobs he could get required hard labor, which he did not enjoy. He had gone to college to avoid these jobs, and now his college loans were forcing him into them.

A couple of weeks after he stopped taking his medication, Pedro decided that if he burned his clothes—a technique he thought might help to get rid of “bad vibes”—he would feel better. Pedro’s family understandably saw his effort to burn his clothes as a complete break with reality rather than an attempt to restore things to normal. They asked the magistrate for another warrant.

This time, the police took him to the county hospital, where he stayed overnight while he waited for a bed at Shady Elms. At the county hospital, he claimed, “the doctor laughed at me. He said I was mania, and I was like, ‘What the hell?’ I go, ‘What’s so funny?’ and I asked him for his license number, and he laughed at me even more. Even his medical student was like, ‘What the hell?’”

Pedro thought the medical student also felt this doctor was out of line. The doctor’s dismissive attitude triggered something in him. Pedro reflected, “It kind of broke me down and [. . .] the next few days I kind of got myself together. And they transferred me to [the state hospital] . . . So I was pretty much in the hospital for a month.” The state hospital, of course: Pedro had no private insurance.

One of my team members asked, “How was that?”

“It was kind of heartbreaking; it was a little bit depressing. But I was able to get myself together and realize what was going on. And then the medication that they gave me originally . . . it would have clogged up my nose. I wasn’t able to breathe. So now they’ve given me a different medication. So now I’m able to breathe and I feel positive about things now.”

“That’s good.”

“With my PTSD, it helps a little bit.”

However, while he was open to his new medication—for his PTSD—Pedro was skeptical of the mental health care he had received. Things did not seem quite right to him:

*PEDRO:* To me, it’s like one of those things that—how can you diagnose that quick?

*INTERVIEWER:* Yeah, you get ten, fifteen minutes maybe.

*PEDRO:* Not just that, but you’re seeing somebody that you don’t know. It’s somebody that just walks in and reads the chart and just throws you out to the side, like you’re a piece of garbage.

*INTERVIEWER:* Yeah, is that how you felt?

*PEDRO:* It just didn’t make sense to me, the system that they have.

Pedro thought he had been diagnosed as “mania,” which he would later call bipolar disorder, but he described his main challenge as “mostly just my PTSD straining me.” He added, “I have ADHD and I’m dyslexic. I’m still able to overcome

things when I really want to do them, and my family knows about that. And college is hard, but if I really put my effort in, I am able to overcome everything.” Pedro’s family knew about PTSD—a diagnosis his father had apparently been given—and that diagnosis was acceptable in their local moral world. For them, PTSD signaled service to one’s country—as when Pedro’s father helped the FBI and served in Vietnam—something to be proud of.

However, he did not feel he had a chance to discuss his “mania” or “bipolar” diagnosis with his doctor. “I was there for three weeks,” he said. “I only saw the doctor twice. That’s something that I didn’t feel comfortable with. I said, ‘What’s the whole point of being here if I’m only going to see a doctor once or twice?’ Then he sees you in front of six other people so it gives you that uncomfortable feeling where you can’t open up. Gives you that feeling where you feel kind of down and you’re like, ‘Okay.’”

Pedro wanted more privacy—something he said he did not get with the college counseling center, either, because he thought the walls were too thin.

*PEDRO:* I would say, in general, even for doctors it’s hard to diagnose people with . . . It’s one of those things that with time and with your life going on—I think, yes and no bipolar exists, but I think there’s other ways besides pills and medications . . . I think with time . . . I do think bipolar exists, but I don’t think it’s as bad. I think some MDs [and] patients kind of exaggerate about it. I think it’s something that with working, having a job . . . I think it’s one of those things that—yes, it exists, but I just don’t think it’s as bad as people make it.

*INTERVIEWER:* Do you think that that diagnosis fits your experience, or are you skeptical about it?

*PEDRO:* In general, I think for them to diagnose people with bipolar, I feel like it should be more than just having a brief conversation with a few people. I think it should be something where you’re able to, not just that, but you’re able to work out, or do this—have more interactions with people for them to diagnose it. I would say it’s not just something that you just sit there, and you have your bed in the next room. I think it’s something that should be more than just that . . . it’s claustrophobic being in the room.

Pedro needed more time and attention from the doctor after receiving a major diagnosis, a diagnosis that put him in “the room” or, as others described it, “in a box.” It was disconcerting and suffocating. Pedro could not breathe.

His first doctor at Shady Elms, Pedro recalled, was nice, which was one of the reasons why he was willing to continue to seek help through mental health care. He described the doctor as Hispanic, which helped Pedro feel a connection.<sup>8</sup> When asked to share more about that relationship, he said: “It was just more interaction with the doctor. He would come in and ask me if I was okay. He would at least see me once a day or every other day.” This personal attention meant a lot to Pedro.

Pedro thought ideal forms of mental health care would include a half hour per day with the doctor and a few other trusted people, such as other patients and family members, “where you can sit down, or play something, and have a few people hang out with you . . . it makes a big difference.” He wanted to have more time engaged with something, “like therapy, where you have different activities, and you can actually express yourself.” He needed relationships, interactions, opportunities for self-expression—a shared moral world—in order to heal.

After his discharge from the hospital, Pedro did attend his follow-up appointments, or “med checks,” though he—like many others—found them unsatisfying:

The follow-ups, that’s another thing. There’s the nurse sitting at the desk; you just go and sit down, and they ask you a few questions that you answer and that’s pretty much it. They check your vitals and that’s it. It’s just a ten-minute walk-in. [. . .] They just ask you the same questions and that’s pretty much it. [. . .] I just don’t want to go in there, sit down, answer the same questions. She’s at the computer typing a yes or no, or I don’t know what she’s doing. I just feel like it’s redundant.

So, why did Pedro continue with care even though he felt misrecognized and misdiagnosed and needed more time and attention? Pedro had decided to apply for “disability,” or a US government stipend through Social Security Disability Insurance (SSDI).<sup>9</sup> According to a US government publication, the Social Security Administration “pays benefits to people who can’t work because they have a medical condition that’s expected to last at least one year or result in death.”<sup>10</sup> Pedro’s father received disability payments to help support the family financially, because he had PTSD, which made it difficult for him to work. Pedro also said that several “college students” advised him that Social Security helped them not have to work while they were also trying to succeed at school. He accentuated that all “the college students” do it and so he was going to try, as well. In his way, even though he was asking for government support, Pedro was trying to maintain his social bases of self-respect by asking for it in a way that was respected in his local moral world.<sup>11</sup>

About two months after Pedro’s first hospitalization, he was adapting to the new medications and applying for disability. He could breathe better on his new medications, but they also initially made him sleep all the time. However, after six weeks or so, he reported, “I’m staying awake more often in the day, so it’s still much better.”

After about four months, Pedro was confident that the medication was helping and described using medications as essential to his health care. He was also delighted to report that he had been invited to his niece’s birthday party. While at the party, Pedro thought the medications made it possible for him to interact with other people and enjoy himself—something he felt had become difficult prior to treatment.

His family did not talk about his illness, though, and they never agreed to meet the research team. “When things change for the better, we don’t like to talk about it,” he explained. “We just kind of let it go. We just don’t like thinking about the past. It’s kind of where you’re like, ‘Yeah, it was a bad scene but blah blah blah.’ We kind of blow it off, you know what I mean? We start over and that’s pretty much how we work. We don’t like to go back unless it’s something real important and we need to go back. We’ll resist something.” For Pedro, his family was a *we*, which was highly meaningful for him.

During his treatment, he continued trying to save money until his school lifted his suspension. He could not afford a gym membership—something he thought would be helpful for young people struggling with mental health issues—so he ran several miles each day in the Texas heat. All the while, he kept his eyes peeled for any sighting of the Liquor Ladies. The local police, he told my team, had promised him that if they came around again they would arrest them and put a restraining order on them. He trusted the police since his Dad had served in law enforcement. Pedro was hopeful that if the Liquor Ladies were arrested, he could finally prove to everyone that it was not all in his head. He especially hoped his school would return his student loans that he lost during the semester when those girls harassed him until he failed his classes.

In his story, we can see how Pedro was slowly securing his moral agency on his own terms with the help of his loved ones. He built up autobiographical power by editing the narrative about his diagnosis and experiences with the support of family.<sup>12</sup> He insisted that he had long-term PTSD like his Dad, that it was nothing new for him, and that his family did not object. The Liquor Ladies were real; the local police were looking for them to arrest them. At the same time, he stopped posting on Facebook about them because he recognized that it was not helping him be seen as a moral agent. Whatever the veracity of these statements, they were helping Pedro heal morally.

With his moral world secure, he accepted medical and material help. He took his medications and applied for social security disability because the cost to his local moral world in doing so was not prohibitively high. The people that mattered to him did not accuse him of being an addict or dependent on the government for accepting these supports. He even claimed that “most college kids were doing it.” Once he stopped sleeping all the time and adjusted to the medications, he was grateful that they helped him interact with people. He went to his niece’s birthday party and had a good time. These were also signals that he was replenishing his social bases of self-respect and expanding peopled opportunities as his family embraced and included him. By editing his story his own way, Pedro replenished his moral agency, at least with his family, and in the process moved toward feeling better.

Not everyone had Pedro’s eventual success navigating the minefields in the post-crisis stages of treatment for psychosis. All struggled with, and at times refused,

the care on offer: the diagnosis, the medications, and for some, the possibility of seeking out disability support. Some seemed to strategically use care to replenish their moral agency in those first few months: these were the treatment users.

. . .

Others ultimately refused care. These young people were treatment refusers. Ariana was one of them. Chapter 4 leaves Ariana's story at the point where she had been forcibly restrained and medicated, was terrified that the world was ending, and was waiting for the hospital chaplain. My research team talked to her again about a week later at the state hospital where she had been transferred (again, she had no insurance).

During that interview, and several that followed, Ariana reflected on her time at Shady Elms. She described being discredited multiple times while trying to tell her own story, which she felt the nurses dismissed as evidence of her delusional paranoia. However, as with Pedro, her paranoia likely had some basis in consensual reality. At the state hospital, she shared vivid stories of "war on drugs"-related violence that she had witnessed as a child, including a man pushed to his death from a moving vehicle and the arrest and imprisonment of her father when she was a young teen. She also shared teenage experiences of sexual assault and a recent miscarriage. She said that her recognizably "Cartel" last name made her a target.

This was "the Conspiracy" that the nurses dismissed during my first attempt to visit with her. It is quite possible Ariana's psychotic break had its roots in repeated traumatic life experiences. However, Ariana told my team that her admission notes (which she had requested) stated only that she was delusional and confused.

"I guess the counselor, whoever that is, he really didn't believe what I had to say about my dad," she said. This made Ariana feel isolated, misunderstood, and dismissed, which eroded her sense of moral agency.

Ariana understood that her thoughts were at times unreasonable. "Right now," she said in her interview at Shady Elms, "I am just paranoid, thinking that I connect all the dots and it leads to all the information, that cartel and that. And sometimes not even in . . . I'm connecting dots that are not even there."

"And you say you're connecting dots that are not there?" the interviewer asked.

"Well I kind of do and I kind of don't."

"Okay, what does that mean?"

"I'm hoping that I am just connecting dots that are not there."

And while she understood that her ideas were "stressing her out," she had few opportunities to work through these ideas in the hospital. "I feel that I'm normal," she explained, "and probably everybody else here feels that they're normal. And I just need, they say, to take a chill pill. And just pray more and read more. [. . .] But they're trying to erase my identity. Who I am. That's how I feel." Many of the young people the team talked with felt as if no one was listening to them or taking them seriously. Rather than feeling heard, they felt erased, even "omitted."

That a psychiatric diagnosis is made by mental health professionals based on their own subjective interpretation of what is going on with the patient presents a problem. At Shady Elms, the psychiatrist on call typically spent about ten minutes with each patient during their stay in the emergency room. They glanced over the notes of the intake nurse and then determined a diagnosis to enter into the electronic health record. This diagnosis was used to decide medical treatment and the length of stay, prescribe medications, bill the appropriate insurance, and make recommendations for next steps in care. If involuntary admission was recommended, the doctor signed paperwork for the judge to evaluate on site (as with Michael). It also factored into a person's ability to apply for a psychiatric disability income later. The diagnosis of a psychotic disorder thus had serious legal, financial, and medical implications. For the young person, the diagnosis also had major implications for their sense of self, their relationships with others, and their perceptions of mental health care.

While looking through the Shady Elms electronic health records to screen for participants, my team noticed that the psychiatrists typically labeled first-timers as having a diagnosis of psychosis NOS (not otherwise specified). However, there was no rule of thumb for arriving at this diagnosis. The psychiatrists I asked at Shady Elms and elsewhere all had their own tools and tricks for assessing which diagnosis to offer, making it seem subjective to outsiders, though perhaps not to a psychiatrist who had been through a decade or so of training.

In addition, psychiatrists and other staff were under pressure to meet with patients and produce the necessary paperwork about risk assessment, suicidality, dangerousness to self and others, and so forth, which, as one psychiatrist told me, "has nothing to do with the patient and everything to do with covering the hospital's ass in case of an accident." The pressures of documentation, the chaotic environment of Shady Elms, the endless line of people needing a diagnosis, and the quality and completeness of the notes made by the intake nurse and treatment team all shaped the doctor's decisions.

This perplexed many of the youths who expected their diagnosis and treatment to be based on tangible scientific evidence. In the American imagination, medicine and its biotechnologies have great potential and engender hope for patients who use them.<sup>13</sup> Americans expect technology and science to be part of their health care. Many youths in our study were skeptical because their diagnostic process (from their perspective) had involved no scientific evidence.

Corrina was one of these people. A few months after her diagnosis, she told me, "I think simply because there are no tests, just like with the rest of medicine, you can be like, 'Okay, you have diabetes. I've done the bloodwork. This is what we do for diabetes.' But with this, it's totally different, because nobody knows what's going on inside anyone's head, psychologically or chemically."

Ariana was also a skeptic. She could not understand how her diagnosis had been made in the absence of any technical evidence.

ARIANA: What was it they diagnosed me again? [. . .] Psychosis.

INTERVIEWER: Okay.

ARIANA: And I looked up the dictionary what “psychosis” means, and you don’t put reality—that you’re living a fantasy life.

INTERVIEWER: Okay.

ARIANA: I’m like, psychosis? I’m here. I’m all here, you know? It’s just, yeah, issues with my Dad was affecting me, which I realized what my Dad did doesn’t affect me.

INTERVIEWER: Right.

ARIANA: How do you know there’s something wrong with my brain when you haven’t actually looked at it? That’s what I’m saying.

INTERVIEWER: Right. Right. Yeah.

ARIANA: I’m like, “Don’t you need to see my brain first to judge it and say there’s something wrong with it?”

INTERVIEWER: Right. Right.

ARIANA: That’s just my opinion. I’m no doctor . . . But yeah, I didn’t like what they diagnosed me with. I guess I’m just going to have to stay with this treatment and prove them wrong. I don’t live in no fantasy life. My life is as real as his.

INTERVIEWER: Yeah. So, how did that make you feel when—?

ARIANA: It just, it got me confused. I’m like, really? That’s what he thinks? Everybody has their own opinion, and that’s his opinion . . . I’m still going to be taking the treatments just to prove them wrong, because how can they know what’s wrong with me when they haven’t gave me, you know, they haven’t gave me a physical or anything like that?

Then the interviewer asked what she thought would be ideal mental health care in the future.

ARIANA: You examine the brain. I’m like, how can you just tell? How can you just say, “Oh, that person’s such and such,” because of what they speak? And like sometimes you can’t express everything you feel. Examine the brain. Look at—you know, I don’t know what they do or what’s the process to look at an X-ray or check all of—what’s wrong with the brain? But like examine the brain first.

*Diagnosis* literally means “to be known through.” Psychosis has no definitive biomarkers like a blood test, and so diagnosis is an interpretive process. With many assumptions being made by the doctor—ideally based on their clinical experience and sensitivity—a diagnosis so made can have a powerful impact on one’s sense of identity and moral agency.<sup>14</sup> For many people, being diagnosed with a highly stigmatized and serious illness based on some intake notes and ten minutes of being asked unusual questions seemed arbitrary and often did not

match their own version of events. Pedro was being stalked by his father's enemies. Ariana was just struggling with the situation with her dad. James's parents were denying the celebrities access to him because they did not want him to become famous. Miranda's parents were keeping her from Sean because they did not want her to grow up.

Given their convictions about what was going on with them, the seemingly quick and severe diagnoses they received only seeded their distrust of the mental health professionals, who they felt did not know them. It was disempowering and sometimes scary for them to be "known" in a way that had such strong implications based on so little evidence.

Corrina described her thoughts about her diagnosis a few weeks after her hospitalization:

*CORRINA:* The one thing that I can say that's really weird is being diagnosed with psychosis unspecified disorder, and that freaks me out a little bit.

*NEELY:* Can you tell us a little more about that?

*CORRINA:* Yeah. He said that I have PTSD and unspecified psychosis disorder, 'cause he can't figure out necessarily what's wrong. So it's just weird. I mean, I don't understand why I feel weird, but at the same time I don't feel bad. It's kind of like floaty, but at the same time I feel happy, 'cause I'm not depressed chemically, so . . .

*NEELY:* So, what does psychosis mean to you?

*CORRINA:* Oh, just a break with reality, I think.

*NEELY:* Yes.

*CORRINA:* It's kind of scary. I don't want to intimidate people or freak them out. I just want to be myself again. I just want to be back to the way I was in high school, but that's not—I don't know.

*Psychosis* is not a word associated with a positive identity in any culture of which I am aware. Once a person has been so labeled, they feel self-stigma and distress. As with Corrina, it makes them doubt who they are going to be in the future.

Amy was also anxious about receiving a diagnosis during her hospital stay. "I don't know what they're diagnosing me as or with, though," she said.

"What do you want them to diagnose you with?" I asked.

"I just want them to just let me go and not diagnose me."

A few weeks later, Amy observed that it would be nice if the doctors could treat a person by using technology of some kind. "It would be nice," she said, "if they could just hook you up to a machine and see which chemicals are off or what's misfiring and just correct it somehow. Maybe just give you some happy pills and send you away."

Over time, Amy replenished her own moral agency by insisting that her Adderall caused her to have some psychosis symptoms but that she did not have psychosis. Notably, though, she—along with everyone I spoke with who was on

ADHD meds—desperately wanted the medication back regardless of the possible connection with triggering psychosis. In this way, Amy retained some control over the diagnostic narrative and became a “user” of mental health services. She, like Pedro, decided she did not have to agree with the mental health professionals’ version of events. Some might say that this signaled she was sick and lacked insight. I believe that this resistance helped her move toward getting better.

It sustains young people’s moral agency to be given more space to shape their diagnoses, especially in the absence of technological ways to “prove” that something is wrong with them. People can experience psychotic symptoms and meet criteria for many psychiatric and organic conditions, including bipolar disorder, major depression, borderline personality disorder, posttraumatic stress disorder, brain tumors, and temporal lobe epilepsy, as well as psychotic disorders. Referring to anyone as a person who *is* psychotic is a culturally loaded term even though it signals a wide range of possible diagnoses. It is not clear that this diagnostic label is at all helpful, given the tremendous societal stigma attached to it. Many people hear “psychosis” or “psychotic,” and they think of psychos and psychopaths—two derogatory terms associated with extreme social deviance and violence emblazoned in the American psyche through popular films like Alfred Hitchcock’s classic *Psycho* (1960).

The term *schizophrenia* or *schizophrenic* is no better. A diagnosis of schizophrenia in a patient record can lead even health care professionals to exhibit stronger negative attitudes.<sup>15</sup> Many societal stereotypes are associated with schizophrenia, including dangerousness, unpredictability, and incompetence, that lead others to have prejudicial reactions against people so labeled. This public stigma in turn can lead people so diagnosed to lose self-esteem, self-confidence, and self-efficacy.<sup>16</sup> Evidence suggests that this also holds true for people labeled as medically *at risk* for developing psychosis—which only shows how much power these terms exert over people’s self-understanding.<sup>17</sup> In addition, public stigma against people with psychosis has gotten worse over time with increasing perceptions that people with schizophrenia are more likely to be violent than those without schizophrenia.<sup>18</sup>

Of the twenty-four people who discussed their diagnosis with my team, six people said they had been diagnosed specifically with schizophrenia. All but one was Black. Only eight Black individuals shared diagnostic information (out of fourteen interviewed), so it is striking that five out of eight had received the diagnosis most associated with dangerousness in the public imagination. Indeed, those who had been given a diagnosis of schizophrenia perceived it as especially persecutory or punitive.

Veronica, the young African American woman whose sister walked her into the hospital to gain access to psychiatric medications (see chapters 3 and 4), viewed her schizophrenia diagnosis as unacceptable. She felt she had been misrecognized and misunderstood:

- VERONICA: I do not agree with the fact that they accuse me of having schizophrenia.
- INTERVIEWER: Accused you of having, that's how you feel?
- VERONICA: It's like you ask for medicine, obviously you may need it. It's like I asked for it because they [her family] told me to go get it, but not because I needed it. I don't talk to myself. Overall, I feel confused about that whole thing. Of all things, you could have said bipolar, you could have said something else, but I have *schizophrenia*.
- INTERVIEWER: Do you have any thoughts on why they did that? Do you have any inking about why?
- VERONICA: Why? Because I hear God's voice, but it's not like an audible voice. It's more like I feel what he's saying. I sense bad things. I sense good things. He lets me know. Whenever they said, "Do you hear voices?" I said, "The only voice I hear is the voice of God." I think that's where it rooted from. I just thought about that. When they asked me that in the very, very beginning, they're like, "Do you hear voices that we can't hear?" I said, "Yes." I forgot. I said, "Yeah. You can't hear them apparently because I'm here." That sucks, but yeah, that's the case. Not to be mean or anything. I was upset. My family was supposed to be there, and they weren't. They were there physically at the moment, but they weren't there.

It is not surprising that Veronica was confused, as were many others. She had been answering questions honestly and felt that her answers had been misconstrued. She "forgot" to conceal her relationship with God from others who would not understand. And her family was not there to help.

Over time, Sofia and her mother worked hard to find a doctor willing to shift her diagnosis from what they described as "schizophrenia bipolar" to "nervous breakdown" or *nervios*—an idiom of distress in Latinx culture associated with traumatic experiences that had less negative weight to it.<sup>19</sup>

- MARIA: Yes, because we did not agree with the diagnosis that she was given, because what happened to her has to do something with fear and stress. How do they call it?
- SOFIA: Like a nervous breakdown.
- MARIA [*continuing in Spanish*]: It's because the doctor who had seen her before was not there that time. Unfortunately, he did not give the attention, like he didn't really care. So then that is why we were so unhappy. He was like, "Here is the medicine," and he didn't have any kind of conversation with her and wouldn't even look her in the face. And I would be like, "well, this is not a doctor." I was very upset and said I wanted to talk to another doctor, and so much that we had asked God, and that doctor was not at work that day. [. . .] We talked to the new doctor and told her that we wanted to keep seeing her. And, right now, we are seeing [about more care] because she is not receiving the therapy, because she needs therapy to be able.

Maria and Sofia needed a doctor to pay attention and listen to their story before they could accept a diagnosis and treatment. They also needed that diagnosis and treatment to align with their cultural values and what they perceived to be a realistic representation of Sofia's experiences. And they, along with the other youths in our study, needed to know that using the mental health services on offer would put them back on the path toward getting better, not weigh them down with a stigmatizing label for life.<sup>20</sup> These are all examples of the moral dimensions of care that are so important for treatment decision making.

There are places in the world where people have tried to shift the stigma that accompanies psychiatric labels of psychosis and schizophrenia. In India, anthropologist Amy Sousa documented how people diagnosed with schizophrenia were never referred to as "schizophrenic" by their care providers, nor by their families, nor in everyday life. Instead, Indian physicians practice "diagnostic neutrality" to avoid upsetting patients and families, since schizophrenia is a highly stigmatized condition that can bring shame on an entire family for generations. Why use such a label when it makes no difference in treatment and can spoil one's reputation and social recovery processes?<sup>21</sup>

In Japan, the term *schizophrenia* has been abolished. Despite a good deal of controversy, in 2002 the Japanese Society of Psychiatry and Neurology changed the diagnostic label of "mind-split-disease" (*Seishin unretsu Byo*), a term for schizophrenia that many argued was outdated, to "integration disorder" (*Togo Shitcho Sho*).<sup>22</sup> The goal was to decrease stigma.<sup>23</sup> Years later, evidence suggests that the change has worked in reducing societal stigma and the negative effects that this stigma has on people's lives.<sup>24</sup> There was also a significant decrease in negative stereotypes about people with "integration disorder,"<sup>25</sup> and they were less often portrayed in media reports as being dangerous.<sup>26</sup>

The United States has seen no move toward an alternative to *schizophrenia* or *psychosis*, even though the terms are heavily stigmatized, not required to access treatment, have legal implications, and are often upsetting to people and their families who fear their negative connotations. Those burdened with these labels must find their own ways to come to terms with the diagnosis. Everyone in our study struggled; some figured it out. If they did not, they could always refuse the label—and the treatment.

. . .

Latuda. Lexapro. Seroquel. Risperdal. Haldol.

Prescribing antipsychotic medications, like determining diagnoses, is also a socially negotiated process between patients, families, and mental health professionals. Some families don't want their children to use medications, especially families that believe people who use medications regularly are "addicts." Others want to "pray it away." Sometimes, the young people in our study did not want to use medications, and their parents used the threat of losing their housing to

achieve compliance. For those who did agree to take medications, questions of which medications, at what dose, and with what side effects had to be continually negotiated with prescribers. The person doing the prescribing changed frequently, especially at the early stages, and was often assigned based on insurance access. Prescribers might include psychiatrists but, outside the hospital, were more often general practitioners, physician's assistants, or nurse practitioners with varying degrees of experience with psychiatric medications.

Many of the young people tried to avoid medication completely when they left the hospital. Some wanted to drink alcohol or not have to take these new medications the rest of their lives. Often, they found the side effects—which could include memory loss, stuffy nose (as Pedro noted), restlessness, itchy skin, excessive daytime sleepiness, sexual dysfunction (such as impotency), excessive hunger, disrupted menstruation, cardiac arrhythmia, postural hypotension, sudden cardiac death, or weight gain—to be intolerable.<sup>27</sup> One study suggests that tardive dyskinesia—or the onset of *irreversible* and uncontrollable twitches and tics resulting from antipsychotic medication use—affects around 7 percent of first-episode patients who use older antipsychotics like Haldol and Thorazine, the same medicine that Corrina was using.<sup>28</sup> This proportion is significant among people prescribed these drugs for short-term use. In the same study, the newer antipsychotics caused less incidence of tardive dyskinesia, but still affected 3 percent of first-episode psychosis patients who used them and were also more likely to cause obesity and type 2 diabetes. One starts to wonder why anyone would take these medications.

Pedro had to be hospitalized a second time before he asked for different medications. The first medications made him feel congested and as if he could not breathe. After his second hospitalization, his family supported him by taking him to follow-up med checks with a nurse and helping him pick up the prescriptions at the pharmacy—support that was needed to keep him on the medications until the side effects were manageable.

Other mental health treatment users in my study had medication-oriented support from their loved ones—typically a family member—as they navigated prescriptions and side effects. Corrina, for example, tried six different medications with the help of her mother Sandra's advocacy, insurance, and support. They talked about this support with me during Corrina's first interview at home, though Sandra did all the talking:

*SANDRA:* Thank God, she's—this is the sixth antipsychotic medication, and this is finally starting to work okay on her. Yeah, we went through six of them.

*NEELY:* That's a lot. It's only been a few weeks.

*SANDRA:* Oh, absolutely. Because she went through one almost every week, every week, every week, and it would get to the point on the weekends I was kind of dreading it because that's when she would just have the reactions and stuff. One of them was so bad, I mean, we thought we were going to have to take her to the emergency room.

*NEELY:* What kinds of—?

*SANDRA:* The tremors, the arching . . . almost convulsing and stuff, because these are heavy-duty drugs.

*NEELY:* They're powerful.

*SANDRA:* Yes. And so we watched her constantly and stuff, but thank goodness this Haldol that she's taking—and that's the minimum she's taken. I mean, and the doctor said, "I can't increase it anymore because you are so sensitive to it"—

*NEELY:* To the tardive dyskinesia symptoms?

*SANDRA:* Mm-hmm. She's highly sensitive to it and stuff. And so it seems to be working okay. She's on a mood stabilizing, the Lamictal, and that seems to be helping her. [ . . . ] They're all supposed to help you just put your computer back in order, and that's the way I tried to tell Corrina. I said, "Think of it as your brain is the computer and you're going through a major overhaul, and so they had to go ahead and unplug it, and they're having to redo every program in there."

*NEELY:* She's rebooting.

*SANDRA:* Yep. Rebooting. Exactly.

At times, Corrina wanted to quit her medications, but Sandra told her she could not live at home unless she took them. In another interview a few weeks later, Corrina shared more:

*CORRINA:* I think I'm at the point where I've realized I can't refuse any help anymore—it's not an option. If I want to keep my lifestyle that I have now, which is—there is no alternative, so you just have to cooperate.

*SANDRA:* Well, there is an alternative, you just don't have a place to—you know.

*CORRINA:* Well, I wouldn't want to go back to how I was. I'd rather just keep going up steadily.

*NEELY:* Okay, so you're not refusing help you're just—

*CORRINA:* Yeah, I'm accepting it.

Corrina also received psychotherapy. She told me that she really appreciated the help of her therapist, especially with stress management. "I think probably the therapist being able to tell me, 'This is how you deal, worrying about this problem.' That really helped because that was one of my main problems. I would just get so worked up and so worried about something, that now I have an experience to draw back on and just calm down. It helps to have that person there now, really reassuring you." Given that psychosis has a lot to do with stress, a therapist who can help the person manage their response to stress is a valuable item to have in the toolkit.

Several young people identified therapy as an important piece of care that they were *not* receiving, regrettably, even though therapists present a peopled opportunity that can help a person work through the grief and shame related to their psychotic break to move toward recovery.<sup>29</sup> One Latina named Lola said what she

wanted most was to receive “a lot of counseling. I think I really need somebody to talk to so I can express my feelings, cause once I talk about it, I feel better. Somebody heard me, you know? And I need someone that’s not gonna judge me or assume things about me.” Finding a nonjudgmental space was hard, but it was important to help restore their sense of moral agency while using care.

Yet, while most young people in my study were not being offered therapy, they were being offered powerful medications that had strong side effects, with few directions about how to deal with them except not to drive for six weeks while they adjusted to their medications, and to stay away from alcohol and drugs. Those whose parents were not helping them understand their medications, advocating with them for better medications with their doctors, or requiring them to take their medications regularly to access material supports like housing had trouble seeing how medications were helpful. Experiencing negative side effects such as slowed thinking or speech that limited their ability to work, go to school, and connect with others further challenged their sense that using medications was a good idea.

Michael, for example, struggled a great deal with side effects and ultimately decided not to take any medications. “I don’t think [the doctors] know what they’re doing,” he said. When the interviewer asked why, he gave an example: “One doctor at [the state hospital], he said that I’ll be able to function if I take the medicine. And, I don’t know, I didn’t really, like, feel able to function.” He continued:

I think he said maybe not all the way back to normal or something like that, but I don’t know. Like, another doctor was, like, “Yeah, you’ll be able to go back to school, and you know”—I don’t know, saying I could go back and talk to friends. I don’t know, just like it’s hard to explain, but it doesn’t feel—like I think they think the medicine will take you back to like normal, like how you were before the illness. But me, if I’m watching the *Today Show* or news, I could see the difference in how I perceive things and how the news is, like how reality is. My reality doesn’t seem the same as theirs.

Michael understood that he had schizophrenia and that he thought differently than the people around him, but the medications—from his perspective—did help him function better. First of all, they made him impotent, and Michael wanted to have a wife and children.

*MICHAEL:* It’s almost better to have the schizophrenia and still have your body parts working like they should. It’s like if something is pros and cons, like, would you still want to have schizophrenia but still have your male organs working like they were.

*INTERVIEWER:* Feel more like a—

*MICHAEL:* Like a man. [. . .]

A few weeks later, Michael was still struggling. “It’s better, like, ‘cause you know now I wouldn’t hurt my family or nothin’ like that, but it’s bad because I don’t feel

good. [. . .] I don't feel normal, so that's the bad part. But it did make me, like, more rational . . . At least I can be with my family, but [. . .] I kinda lost my identity. [. . .] I lost my personality. Like I don't know who I am really."

Michael's family listened to his concerns. They wanted what was best for him. The doctor told Michael he needed to take his medications for life, but neither he nor his family could imagine a life with the medication's side effects, and no one liked who Michael became after the psychotic break, which they associated with the medications. In the absence of any signs that he might harm them, they decided he could stop taking his medications after five months or so. Michael's family did not seek additional mental health care, and Michael became a treatment refuser. The team did not see him again after that point.

Other young people had doctors who helped them see the value in their care, especially by helping them tinker with their medications—changing, adding, taking away, tapering. This seemed to help people want to stay in care. Four months into the interview process, Gideon mentioned that he continued to use mental health care because he had a good relationship with his prescriber:

*GIDEON:* I talk to her, and we talk about my life. What I'd mention is working, what is not working, what is giving me fat . . . For example, the medicine I used to take is getting me all plumped up, a little bit, so she was like, "Let's cut it off." I like her, I like her a lot; she just told us, "Cut it off," because I hated our medicine, makes you sleepy. [. . .] See, last time you came, I was really sleepy.

*NEELY:* Yeah, you were really sleepy.

[. . .]

*GIDEON:* I'm taking a new one, which doesn't make me feel sleepy, it makes me active and everything. [. . .]

*NEELY:* Have you had the same [prescriber] the whole time?

*GIDEON:* I used to have [a different prescriber], but she wanted us to take things slower because she didn't want to take the meds off. This one, though, she listens to you, she does things fast for you . . . I just like the new one because she listened to me, and she cut off the medicine, and she'll give me a new one. [. . .] They're just doing their best to try to make me better. I don't feel anything. I actually enjoy going to her now. We can talk, she answers what's going on.

Clearly, an interactive partnership with his prescriber helped Gideon to navigate his side effects and to choose to use treatment. He saw some of the benefits of his medication, but he needed time and a supportive prescriber to really move forward in the process. Gideon was able to find one after his original prescriber "left" (they did not tell him why or where) and he was assigned to a new provider. Gideon had regional insurance.

Ariana refused further mental health care, including medications. It wasn't so much the side effects, though by the third week she was complaining that "the medicine makes me feel like a robot." She knew she should probably go back to the doctor and ask for a lower dose, but no one encouraged her to do so. But what really made her dismiss medications was that her local moral world was not supportive of people who used medications. Her family made fun of her visit to the "crazy house," and a coworker gossiped about her. The stigma at work became so intense, she quit her job. Ariana also worried about developing a substance use disorder like her Dad.

Ariana had originally wanted to prove to the doctors that she was not out of touch with reality by being a "good" patient and taking her medications, but after it had serious social consequences, she decided instead that she wanted instead to prove the people wrong who were gossiping about her. So she quit her job, even though she was finally making enough money to save up for college, stopped taking her medications, and drove to another state to help her brother with his new baby—a fresh start.

Ariana took back some autobiographical power by dissociating herself from mental health care and calling it all a mistake. She found a meaningful social role by caregiving for her nephew, which was also a peopled opportunity. Her family was instrumental in making this happen. They gave her a chance. What is important here is that refusing care made more sense in Ariana's local moral world, as it did in Michael's and in many others. Ariana hoped that family support would be enough to help her get by without medication. For as long as the team was in touch, it was working out.

Other young people in our study also mentioned their fears that using medications was a kind of addiction. Lucia, the young mother who had to stop nursing, quit taking her medications after her husband accused her of "popping pills"—an activity he compared to abusing oxycodone.

Others who had been abusing substances prior to their hospitalization were confused that they had to use more chemicals to get better. As one white woman who had a cocaine use disorder said, "I feel like I'm not really sober to have this to medicate with. But [the doctors] are like, 'No, it's different when you have a prescription!' [The doctor is] like, 'You don't want to hear voices again, do you?' I'm like, 'No.' He's like, 'Then, you have to take this.' Yeah, I've been on that since I got out of the hospital."

Young persons whose families had a negative perception of psychiatric medications or of people who used them typically refused mental health care. Keep in mind that their family is often the only material and moral support young people have when they are discharged from the hospital. Coworkers, roommates, and friends have often disappeared or are gossiping about them—or at least that's how the young people the research team interacted with saw it. If their family did not

want the young person to pursue mental health care, then it was not at all clear to them how using medications or seeing additional mental health providers would help them be seen as good people in the only local moral world to which they still had access. Back home was the place where many of them had felt safe before they tried to go off and make their own way in the world. Many needed to feel well received in that context at least.

Some young people who refused treatment had families for whom using medication signaled a lack of religious faith. Markus's parents were divorced. His father was African American, and his mother had immigrated from Africa. Even early on at the hospital, when asked about ideal mental health care, Markus indicated that he was not planning to use medications for his psychosis. "Hmm," he said in an interview, "if mental care was better, maybe if they prescribed less medications and spoke to more people about their issues, I think that would be better. Because some issues can't be solved by medication unless it's like a biological thing."

Over the next several months, Markus's mother, Hazel, also maintained that he was under spiritual attack by a jealous relative who had sent a powerful curse his way. She believed his problems were caused by demonic forces. When asked about whether Markus was using medications, Hazel replied:

No, [Markus] is not on any meds right now, and really, to be honest with you, he doesn't need any medications, but spiritual intervention is what he needs, and he is getting it. So I may sound naïve to layman Americans. They will be like, "She is crazy—what the hell is she talking about?" But I am in the medical field, and I know what I am talking about, because the root of his problem is not physical. It's not physical.

Hazel explained that she used the hospital strategically as a kind of holding tank—a place to keep her son safe when he seemed dangerous. She dropped him off but did not go with him or visit, because "there is no point pouring water on a stone. Right? If you want to pour water you want it to sit and collect; there is no need discussing it because [the medical professionals] won't understand it. Where will I start? They won't even understand it. So I let them say whatever they want. [. . .] Admit him. Fine. All I needed is shelter, and then I'll go back to my praying place and start praying."

Hazel fasted and prayed for him while he was away. Then, when Markus was discharged from the hospital, she explained,

they do referral for him to follow up and stuff like that. Then [Markus says], "Oh, mum I'm not going to do it. Mummy, I'm not doing it. I'm not taking these medicines. I'm not going there; I'm not doing this. I'm not." And I don't force him; the reason why I don't force him is because he doesn't need medical intervention. [. . .] I'm into now praying that God should intervene completely, so he can be a normal kid and go back to school, and finish. You know, God is in control.

Markus remained a refuser throughout the study. It made no sense in his local moral world of family and church to do anything besides pray for a total intervention from God to alleviate the intense spiritual attack on him. The one thing his mother thought would be helpful was a life coach—someone could advise him to study and continue to better himself. She thought it might be especially helpful to hear more about people who had experiences like Markus's but were also successful so that he would be encouraged by their stories and learn some strategies for success. This option made sense to Markus, his church, and his family—his local moral world—as a way to boost his moral agency and material resources; medical interventions like accepting psychiatric labels and medications did not.

I hope it has become clear that diagnostic neutrality or flexibility can be helpful for moral agency. Flexibility around pharmaceutical and psychosocial options for treatment is also needed. It is no longer medically true that a person who has psychosis needs absolutely to be on medications the remainder of their life, but this is not always clear to youths. It is not even clear to prescribers, who have varied levels of knowledge about psychosis. The literature itself is confusing and often contradictory. One study on young people experiencing early psychosis found no difference, at a two-year follow-up, between treatments that used antipsychotics and psychosocial interventions together, and treatments that used only psychosocial interventions.<sup>30</sup>

It does seem that being prescribed antipsychotic medications with powerful side effects for the rest of one's life in order to treat a psychotic disorder at times does not support people's moral view of themselves or what it means to be a good person. It uses all the wrong terms and ignores the strategies that young persons and their families employ to remain well morally—which they often choose over medical wellness when they perceived the two as conflicting. Longer-term research with a larger sample is needed, but this work calls into question whether medications are necessary if good moral supports are in place. It also suggests we may need to do more research on who is responsive to psychosocial supports, which ones, and why. I anticipate that the ways those psychosocial supports align with and even enhance what is upheld as good, beautiful, and true in the person's local moral worlds is key.

. . .

The young people in our study who used care did so because it made sense in their local moral worlds. They needed to restore moral agency by accessing autobiographical power, the social bases of self-respect, and peopled opportunities to work toward living meaningful lives as valued adults. Even if they were often not able to choose their initial diagnosis and treatment, they did want to choose the relationships with people who defined what it meant for them to be a good person, and they wanted to be seen as moral agents in the eyes of loved ones. This

TABLE 1 Frequency of factors that participants identify as key to treatment decision making

Factor	All participants (N = 37)			Young adults (N = 18)			Key supporters (N = 19)		
	Rank	N	%	Rank	N	%	Rank	N	%
Desire to get back to normal	1	36	97.3	1	18	100	1	18	94.7
Care on offer is not enough	2	29	78.4	4	13	72.2	2	16	84.2
Police involvement	3	26	70.3	3	14	77.8	3	12	63.1
Feeling worse	4	25	67.6	3	14	77.8	4	11	57.9
Relationship repair	4	25	67.6	4	13	72.2	3	12	63.1
Paying for care	5	23	62.2	2	15	83.3	6	8	42.1
Living independently	5	23	62.2	3	14	77.8	5	9	47.4
Distrusting diagnoses	5	23	62.2	5	12	66.7	4	11	57.9
Social substance use	5	23	62.2	5	12	66.7	4	11	57.9
Feeling disempowered	6	21	56.8	3	14	77.8	7	7	36.8
Transportation issues	7	20	54.1	5	12	66.7	6	8	42.1

SOURCE: "Table 3: Ranking of factors identified by young adults and key supporters as affecting treatment decision making after the young adult's initial hospitalization for psychosis," in Myers et al., "Decision Making about Pathways through Care," 187.

drove their decisions whether to accept treatment, regardless of whether they were users or refusers.

In fact, contrary to my early expectations, there were not many clear and striking differences between the lived experiences of users and refusers prior to initiating treatment or during their early hospitalization experiences. Both groups had extreme symptoms and serious emergencies leading up to their hospitalizations. Each group had both positive and negative experiences of hospital care. Both questioned the science behind the diagnostic process. Both experienced difficult side effects from psychiatric medications. Both resented and resisted their diagnosis and the stigmas, the stereotypes, and the questioning of their ability to be in touch with reality and their ability to be a good person. Both wanted to reconnect with family, friends, and employment and educational opportunities as quickly as possible. My team analyzed the data from 37 participants—18 young persons and their 19 key supporters—to identify what was most important for them in terms of treatment decision making, separately and overall; table 1 summarizes our findings.

Strikingly, everyone—users and refusers, youths and families—wanted to “get back to normal,” however that was defined in their local moral worlds. The difference lay in whether they saw using mental health care as a means to that end. I have previously referred to pathways *to* care—the ways that people first came into contact with the mental health care system. Here, I am referring to the pathway *through* care—a pathway that helps people get back to normal, to their everyday

lives, and so move on from the fallout of a psychotic break.<sup>31</sup> In most of my work, pathways through care highlight how we can keep young people engaged in services that they need. But writing this book has made me realize that—for some—this pathway means refusing services.

Refusers needed, more than anything else, care and support from other places—most especially their family. They relied mostly on moral and material, instead of medical, support because either medical support was not necessary to gain access to moral support or because it impeded that access. It is likely that most young people would benefit from all three forms of support, but service providers need young people and their families to be on board morally to make that happen.

Changing how youths and families and society at large perceive medications or diagnoses is not easy. There is not one obvious intervention for all. Change will require following the old social worker adage of “meeting them where they’re at,” but also knowing where they want to be, and with whom, and how to help them get there in a way that is meaningful to them and the people they want to care about them, gently and over time.

People who used care and came to appreciate it, such as Gideon, Sofia, and Miranda, had prescribers who were more flexible about diagnoses, medications, and dosages. The people who stayed in care often described shopping for a provider until they found one who listened to their concerns. Therapy was also an important component of the care that users found to be helpful, but not all insurance covers it.

As is true for many of the problems I unpack in previous chapters, there are solutions available. Many of the solutions brought up by the youths in my study pointed toward the family offering material and moral support, as well as well-informed medical decision-making encouragement early on. The following chapter takes us out of the hospital and focuses on what happens when young people return home and how challenging efforts at this stage can be for youths and families trying to get back to normal.