

# Cultural Chemistry in the Clozapine Clinic

We see that recovery is an important and fundamental phenomenon. Although the phenomenon will not fit neatly into natural scientific paradigms, those of us who have been disabled know that recovery is real because we have lived it.

—Patricia E. Deegan, “Recovery: The Lived Experience of Rehabilitation”

The clinic in which I was conducting research from 1998 to 2004 was the focus of great media fanfare as the first American site to use a new “miracle drug” for the treatment of schizophrenia. The clinic was featured in the cover story of the July 1992 issue of *Time*, “New Drug Brings Patients Back to Life,” in which clozapine was touted as a “magic bullet.” A related article in the same issue was titled “Pills for the Mind.”<sup>1</sup> The *New York Times* published an article that advocated greater access to the new miracle drug, saying, “Many who treat schizophrenia believe clozapine is the most important medication to come along in 30 years. The press is so excited, it keeps using ‘Awakenings’ in headlines, conjuring images of film star Robert De Niro taking a new medicine suddenly going from comatose to superstar.”<sup>2</sup> The *Harvard Review of Psychiatry* drew attention to the phenomenon of “awakenings” as an unprecedented therapeutic challenge: “often involv[ing] a fundamental reassessment of one’s identity, relationships, and purpose in being[,] . . . [t]he psychological reaction to dramatic pharmacological response is largely uncharted territory” (Duckworth et al. 1997: 55).

Charting this territory required research involving persons ingesting psychotropic drugs to ascertain their myriad cultural, social, psychological, and biological effects. From an anthropological point of view,

this required looking beyond the “main effects” of symptom control. What was needed was a detailed account of the lived experience of those who take these drugs, specifying the social and cultural contexts of claims of drug efficacy. There are several immediate questions from the perspective of persons taking them: How do they work? What are their effects? Do they really help? Are they transformative? What is their meaning? Can drugs really “mean” anything to people? How, anthropologically, could they not? Whyte and colleagues (2003) have intriguingly written of the “social lives of medicines,” but what could *that* mean in the case of psychotropics? Are they like the late-night cavorting yams of the Dobu in Papua, New Guinea, that are magically enticed into a neighbor’s garden (Fortune [1932] 1963)?

In this chapter I present ethnographic evidence to address these questions, but first I must outline my general approach to the understanding of psychopharmacology in contemporary global societies,<sup>3</sup> which is predicated on recognizing the interrelation of several levels of analysis, including (1) the *subjectivity* associated with medication use, where subjectivity is understood as the relatively stable yet transformable structure of experience; (2) the potential of psychotropic drugs to affect the *self*, where self is understood not as a discrete entity but as a configuration of processes by which people orient themselves to their own being, to others, and to the surrounding world; (3) the context of *culture*, in which the power of cultural meaning involves nothing less than the ability to shape the experience of agony and monotony, relief and recovery, identity and lifeworld among those who take these drugs; and (4) the *institutions* in which drugs and illness are embedded, including biomedicine, government, nongovernmental organizations (NGOs), insurance companies, the pharmaceutical industry, and the policies and practices of employers.

In this analysis, what sense can there really be to an assertion of a critical interrelation among subjectivity, self, culture, and institutions for an understanding of psychopharmacology? *What* are psychiatric medications really for? Unbearable suffering? Supplemental nutrient? Demonic affliction? Neuronal misfires? Personality deficits? Bad behavior? Violent behavior? *Who* are they for? The afflicted who find medications a relief in quieting unrelenting voices? Exposed populations of the elderly, children, indigent recipients of health care, and the mentally ill who are incarcerated?<sup>4</sup> In such cases, subjectivity is constrained by institutional structures of global capitalism in tandem with historically deep societal assemblages for social-political control and also in the service

of establishing “the normal” (Foucault 1965, 1977; Deleuze and Guattari 1988; Rhodes 2004). This latter question of course concerns not only the use but also the misuse of psychotropic drugs.<sup>5</sup>

None of my cultural analysis is intended to deny or ignore that there are myriad biological processes critical to drug response. Neuroscientific research on correlates, mechanisms, substrates, and biological contexts of psychopharmacologicals has become voluminous (Ng et al. 2013; Stahl 2013). The field of pharmacogenomics, or the way genes influence response to drugs, may shed light on differential individual and group effects, as may the emergent fields of interpersonal and cultural neuroscience (Schore 2003; Lende and Downey 2012; Narváez et al. 2012; Chiao et al. 2013). There are a host of individually variable features of cognition, personality, and the unconscious that are likely to mediate drug response. A significant part of this variation might be explained through emergent theories of epigenetics as the chemical and environmental “turning on/triggering” or “turning off/inhibiting” of genetic codes. Further, in clinical trials, there is the problem for pharmaceutical companies of the statistical “noise” that is the well-known yet little understood “placebo” effect. In line with my approach here, a compelling interpretation conceptualizes the placebo effect as a kind of “meaning response” (Moerman 2002). Ultimately, to theorize the effects of psychoactive drugs, we need a model of the effects of psychopharmaceuticals that is grounded also in the “tuning” of biochemical response inseparable from the “tuning” of socioemotional response, cultural meaning, and ecological constraint. A wide-ranging model is required since surely all are at once integral to experience, to disease and illness processes, and to outcomes.

Within this framework, while we are compelled to attend to the magnitude of what can be an excruciating experience, no less critical are the lengths to which people go to seek relief and to alleviate this suffering, since healing and transformation are no less characteristic of the human condition than are intractability and misery. In the case of mental illness, for better *and* for worse, the practice of taking psychotropic drugs has increasingly become a central part of the process of seeking relief. Moreover, recovery or at least improvement over time—with and without psychotropic drugs and characterized by great endurance and struggle—is a reality for many people, though the subjective experience and cultural interpretation of the bodily and social effects of medication is anything but simple and straightforward. Finally, taking psychotropic drugs is not merely a routine and pragmatic process of the self. There is

marked existential struggle and sociocultural contestation surrounding identity, power, and medication. The decidedly social-relational experience and meaning of medications requires elaboration. As a step in this direction, let us look again at the media attention to the introduction of atypical drugs highlighted at the outset of this chapter.<sup>6</sup>

#### CULTURAL REPRESENTATIONS OF ATYPICAL ANTIPSYCHOTICS

The heralding of clozapine for use in the treatment of schizophrenia in the United States in *Time* magazine offers a glimpse of the two-edged popular appeal of the story. On the one hand, reference in the article to the medication as a “magic bullet” conjured the notion of dramatic and much desired improvement that had not occurred through prior use of other medications. The article was quite specific in portraying this drug as a new weapon in the scientific-medical armamentarium, invoking a militaristic metaphor of “a fight” against disease (see Martin 2001) through the highly valued medical competence of physician-scientists (M. Good 1995) while at the same time invoking the idea of magical technique. On the other hand, the christening of this particular medication as a “miracle drug” conjured the notion of a substance imbued with the power to bring patients back to life, invoking not only the power of pharmaceuticals but also the religious metaphor of miraculous healing. The anthropologist will likely see these symbolic connotations in light of Malinowski’s (1954) classic discussion of the blurred conjunction of magic, science, and religion in the production of cultural meaning. The historian will most likely be reminded of the intimate connection between alchemy and chemistry in the history of pharmacological treatment. Contemporary discourse on psychopharmacology is steeped in a robust historical link between magic and chemistry.<sup>7</sup>

The other side of this cultural representation, however, is far from celebratory insofar as *Time*’s depiction taps into cultural imagery associated with an all too familiar social stigmatization of the mentally ill. The reproduction of social stigma is evident in two ways. First, in invoking a Christian allusion to resurrection (Wallis and Willwerth 1992), the apparently promising image of healing is embedded in the brutal presumption that persons with schizophrenia had somehow previously been “dead.” It is difficult to imagine any social designation more offensive than reference to persons with schizophrenia as not among the living. Second, there is the notion that persons with schizophrenia are not

really human but somehow alien. All too often this appears to mean that “they” must lack fundamental human capacities for subjective experience of the self, emotion, and social attachment; such assumptions are not only empirically false but also constitute a punishing cultural conception of persons with mental illness (Jenkins 2004; Kring and Germans 2004).

Another point of emphasis in the *Time* article was the sense of newly found possibilities to reach developmental milestones missed because of illness, such as participating in a cultural rite of passage like one’s high school senior prom. In this bionarrative (see Carpenter-Song 2009a, 2009b), not having done so because the ravages of schizophrenia represents a biographical gap, which the promise of clozapine offered to fill. The article featured a staged event of a “better late than never” prom held for clozapine patients. One young man is shown dancing, presumably enjoying himself enormously, though his dance partner was a hired dance instructor and not a personally arranged date of the sort one imagines for oneself at a high school senior prom.

The *New York Times* article on clozapine (Winerip 1992), drawing on celebrity images of Robin Williams and Robert De Niro in Penny Marshall’s 1990 film, *Awakenings*, reported that media and medical excitement was momentous because former patients could go from “comatose to superstar.” The film had been advertised as a “true story” based on the book of the same title by the neurologist Oliver Sacks (1973) that invoked the image of Washington Irving’s (1882) Rip Van Winkle to tell a story of institutionalized patients who became catatonic after having encephalitis. They experienced a dramatic but sadly temporary improvement through another “miracle drug,” L-Dopa. The film ends with the protagonist physician standing over the protagonist patient behind a magical Ouija board, directing the patient’s hands with the invocation, “Let’s begin.” The posters and trailers for the film, like the media coverage of clozapine, had tapped into the appeal of miracles and featured the theme of triumph with the opening of new, blue horizons. Reliance on religious language and symbols, along with magical practices, to convey scientific developments in medicine suggest the relevance of the association between these domains as critical to psychiatric discourse and practice.

Posing challenges to the scientific community, the *Harvard Review* article by Duckworth and colleagues (1997) urged the exploration of “awakenings” as a clinical phenomenon for understanding the dramatic change and subsequent developmental challenges that could occur.<sup>8</sup> Could “awakenings” be understood solely through resort to psychiatric

science, or did realms of the unknown somehow come into play? Was the term *awakenings* merely a literary device to refer to psychological and social processes that could be accounted for biologically when induced by drugs? While in the 1992 *Times* story the clozapine proponent Herbert Meltzer was careful as a research psychiatrist to point out that recovery is not an overnight phenomenon, in speeches to advocacy groups and conferences he too deployed the term *awakenings*. Malinowski's intuition about the relation between magic, science, and religion is hardly restricted to small-scale societies. Indeed, a Zenith Goldline Pharmaceuticals advertisement for clozapine in the *American Journal of Psychiatry* promoted the drug by juxtaposing primitive "myth" of early hominids to modern "fact" in the form of scientific gold.<sup>9</sup>

#### TOWARD THE STUDY OF CULTURAL CHEMISTRY

Clozapine (brand-name Clozaril), the first atypical, or second-generation, antipsychotic developed, was intended for patients who had little or unsatisfactory response to typical, or first-generation, antipsychotics (primarily phenothiazines such as Thorazine, Mellaril, Stelazine, and Prolixin). Clozaril was also used to replace another drug commonly prescribed during the 1970s, Haldol (haloperidol), a butyrophenone derivative with pharmacological effects similar to the phenothiazines. In addition to the claim that it modifies positive symptoms of psychosis better than previous drugs, clozapine was said to have lesser extrapyramidal effects such as tardive dyskinesia and akathisia. Clozapine had already been introduced in Europe in 1971 but was withdrawn from the market in 1975 in the wake of cases of agranulocytosis, some fatal, involving dangerously depleted white blood cells. In the subsequent decade, most clinicians did not look upon clozapine favorably. Following trials that claimed both clinical efficacy and procedures for monitoring blood levels, along with approval by the U.S. Federal Drug Administration (FDA) in 1989, Sandoz Pharmaceutical Corporation brought the drug to the U.S. market in 1990. The drug was promoted as particularly efficacious for conditions of schizophrenia that were considered "treatment-resistant" or "last resort" (Alvir et al. 1993) and prescribed despite the additional risks of seizures, myocarditis, and weight gain. Heady hope accompanied the steady desperation of patients, families, and clinicians dissatisfied with typical antipsychotic drugs. The possibility of improvement appeared to eclipse the substantial risks involved. Clozapine was soon joined on the market and in the clinics in which we were conducting ethnographic

research by other atypical antipsychotics such as Risperdal (risperidone), Zyprexa (olanzapine), and Seroquel (quetiapine), along with other drugs such as Geodon (ziparsidone) and Abilify (aripiprazole). Currently, these atypical antipsychotics are prescribed far more commonly than clozapine. Overall, the number of people using atypical antipsychotics increased from 0.3 million in 1996 to 1.6 million in 2001 (Zuvekas 2005). A recent report indicates that Abilify ranked number 1 in sales for *all* pharmaceuticals sold in the United States (IMS 2014).

The introduction of clozapine marked an important moment in the history of psychiatry and psychopharmaceutical medication. The 1960s had seen conventional antipsychotic drugs alter institutional methods of treatment, followed by mass deinstitutionalization of patients. Total available hospital beds declined from 550,000 in 1956 to less than one quarter of that number by 1998 (Eisenberg and Guttmacher 2010).<sup>10</sup> The introduction of the atypical antipsychotics in the 1990s—along with a patently neoliberal turn with respect to what constitutes treatment—served as the grounds for dramatically raised expectations for improvement, and indeed “recovery.”<sup>11</sup> In early twentieth-century psychiatry, Emil Kraepelin set forth claims that until recently have held clinical authority as applied to schizophrenia (or dementia praecox). He conceived the condition as an inherently chronic and degenerative disease for which improvement, let alone recovery, was all but impossible. Kraepelin wrote that in the great majority of cases, periods of improvement did not last longer than three years and that over time the proportion of cases constituting recovery consisted of a mere 2.6 percent; deterioration and degeneration were nearly inevitable (Kraepelin 1919) By the early twenty-first century, a stark reversal of this clinical outlook was evident in the vision statement of the New Freedom Commission on Mental Health in which recognition of recovery appeared not only as a possibility but also virtually as a mandate:

We envision a future when everyone with a mental illness will recover, a future when mental illnesses can be prevented or cured, a future when mental illnesses are detected early, and a future when everyone with a mental illness at any stage of life has access to effective treatment and supports—essentials for living, working, learning, and participating fully in the community. (2003: 9)

Whereas the introduction of first-generation antipsychotics was accompanied by the social process of deinstitutionalization (Rhodes 1995), the introduction of second-generation antipsychotics was accompanied by

the cultural concept of recovery (Jenkins and Carpenter-Song 2005; Myers 2015).

Unsurprisingly, the long-standing Kraepelinian doctrine of progressive deterioration has hardly disappeared. Schizophrenia is often represented as an inescapable inferno akin to what Hector Berlioz portrayed in *La damnation de Faust*. Clinical delivery of prognosis can likewise be tormenting, as for example when the British psychologist Eleanor Longden was given a diagnosis of schizophrenia and told that it would have been better if she had cancer.<sup>12</sup> Needless to say, such crass pessimism can be crushing to vulnerable persons in states of severe psychic distress. And while the introduction of notions of recovery has opened a potentially significant alteration of clinical-cultural thinking, its coexistence alongside presumptive chronicity and defect has led to what I have identified as paradoxes of lived experience. Persons struggle with competing messages of recovery and incurability that create confusion and intolerable “double binds,” as I argue further below. As a researcher, I have been taken aback more than once by clinical assumptions regarding not only prognosis but also presumptions regarding the subjectivity and fundamental human capacities of persons diagnosed with schizophrenia.<sup>13</sup>

With processes of subjectivity in mind, I see the need for attention to what I am calling *cultural chemistry*, whereby culture is understood as a petri dish for the cultivation of biology, desire, meaning, social practices, and institutions that together constitute what Deleuze and Guattari (1988) call an “assemblage” that shapes response to drugs and illness. Within this cultural chemistry, psychotropic drugs are variously represented—as “mind food for gastrointestinal nutrition” in India (Ecks 2013) or as “medication for chemical imbalance” in the United States (Jenkins 2010). In the United States especially, the cultural chemistry of treatment for mental illness is complicated by deep divides across social, economic, and political interest groups of patients, doctors, advocacy groups, governmental agencies, insurance companies, and pharmaceutical corporations. Everyone has differing goals and information, and those with the most at stake—people who actually take the medications—are the most neglected. The most vital information is not to be found in the package inserts provided by drug companies, publications in health science journals, or even recent black box warnings mandated by the Food and Drug Administration but must be obtained and revealed from the perspective of the lived experience of those taking the drugs. As we shall see, determination of the social and existential facts surrounding atypical antipsychotics is culturally



complicated, calling to mind Oscar Wilde's quip that "the truth is rarely pure and never simple."

#### THE SUBJECTIVE EXPERIENCE OF ATYPICAL ANTIPSYCHOTICS

My ethnographic study, "Subjective Experience and the Culture of Recovery with Atypical Antipsychotics" (SEACORA), addressed the use of atypical antipsychotic medications in the United States for conditions diagnosed as schizophrenia and schizoaffective illness.<sup>14</sup> My primary study site was the first clinic in the United States to be organized and promoted as a Clozapine Clinic. Nevertheless, over the course of our research project, the clinical prescribing patterns expanded beyond clozapine to include other atypical antipsychotics. This chapter therefore presents the experience of persons taking a variety of these "second-generation" drugs.

Large by ethnographic and qualitative standards, SEACORA was a six-year study (1998–2004) with ninety research participants. It was conducted in northeastern Ohio in close proximity to a major research university located in an urban district consolidated in the late nineteenth century as a center for a variety of educational, medical, musical, and cultural-historical institutions, with a surrounding park and lagoon. Within this locale, many participants in our study frequented one site in particular, the Clubhouse, an architecturally elegant three-story building in operation since 1961 as a psychosocial rehabilitation center for persons who live with mental illness. One of the first such centers in the United States, it is a member of the International Network of Clubhouses, part of the social justice movement founded by Fountain House in New York City in 1948.<sup>15</sup> In contrast, the two clinical settings in which participants received their outpatient care were located ten minutes away in a nondescript two-story commercial building in a suburban residential area of the city. On a warm day the distance was not significant when using public transportation; however, on a blustery or snowy day during typically long winters, travel was less comfortable.

We did not rely on clinical records but rather research diagnostic criteria to identify persons with schizophrenia or schizoaffective disorders, using the Structured Clinical Interview for DSM-IV (SCID). Subjects recruited to participate did not have a recent history of substance abuse (minimally the past two years) and were in regular outpatient psychiatric treatment. The study was carried out by an interdisciplinary research

team whose goal was to go wherever the study participants went on a daily basis. This meant spending days in outpatient clinical settings, the community Clubhouse, homes, fast-food restaurants, drugstores, and parks, as well as walking the streets and riding the bus. In addition to recording detailed ethnographic observations of routine activities, we took systematic notes on interactions with peers and treating clinicians, group therapy sessions, and social activities organized by the clinics and the Clubhouse. Through the ethnographic observations we learned that many of the participants had regular social contact with others who were in the study. This frequently occurred in the form of routine visits to the Clozapine Clinic, where there were daily group therapy activities and customary hanging out by participants. The group therapy sessions were facilitated by one of two nurses who worked at the clinic, and the character and content of these sessions tended to vary in relation to which nurse facilitated and who happened to be present. At the request of the female participants, there was a women's group that was organized as a forum to discuss what they agreed was better not taken up in the presence of men. During these sessions, for both men and women and women only, we recorded detailed observations and verbatim comments that are rich, poignant, and filled with instances of outright resistance and hilarity (see Jenkins 2010b). From our daily presence in the clinic we became part of the scene and got to know who was friends with whom, who was going out with whom, who were desirable (and undesirable) sexual partners, and how clinical staff were regarded.

While the Clozapine Clinic was on the second floor of a commercial office building that was nondescript, the interior social atmosphere was anything but. Exceptional paintings by clinic clients covered the walls, and bulletin boards were covered with announcements of extracurricular events and photographs from field trips and holiday parties. The social composition was a mix of clinic patients, nurses, the psychiatry director, family member volunteers, and the SEACORA team of researchers. Of course, not all the various social members were present at all times, but a usual scene might consist of perhaps thirty. Appointment times were loosely scheduled. There was a good deal of hanging around, when social interactions were informal. If not in a therapy group or individual meeting with a nurse or psychiatrist, client hanging out often had no specific activity and might not have included much in the way of conversation. Even so, people made friends and had conversations both inside and outside the clinic. In the hallways and waiting areas, some people were well-known "talkers" who tended to dominate

social encounters. Abby, an imposing thirty-nine-year old Euro-American woman (diagnosed with schizoaffective disorder) was one such talker. Some of her talk was spontaneous, but much of it was canned. In the women's group, others routinely told her they were annoyed that she kept repeating the same stories. This was true of some of her jokes too. When I first met her (in 1999) she saw the opportunity to add to her audience (if not her repertoire) and greeted me with one of her standards: "Hey, when you talk to God it's called prayer, but when he talks back it's schizophrenia!" Humor was common, and the comedic aspects of clinic social interaction are discussed elsewhere (Jenkins and Carpenter-Song 2008; Jenkins 2010b). Like many clinic participants, Abby had an active relationship with her voices. While some of them bothered her and were "not nice," she was quite fond of others, particularly someone she called "Mr. Steve Stallion." The relationship she had with Steve was remarkably similar to her relationships with people in the clinic, to whom she frequently and repetitiously communicated her appreciation of how attractive they looked on any given day: "You look so pretty today. Did you know?" With Steve, she appreciated the way he talked to her, describing what he said to her and how she felt:

Well, every time I put makeup on in the morning, he says, "Boy, you look pretty today. Why don't you put a little bit more here? Put a little bit more there." I go to bed at night and he always says goodnight to me. And he likes Patsy [Abby's cat]. *And* he's really cute.

That sort of talk was often a prelude to her next stock sets of comments that could get downright bawdy.

Gossip was a common social currency, for example, in comments routinely relayed to members of the research team: "I don't like her. She accused me of being a bisexual." Or, "She can't keep her pants on. Maybe it's [related to] the medication." Some comments evinced social competition and comparison, including self-references by thirty-two-year-old Brady, a semibald Euro-American man with a diagnosis of schizophrenia, who pointed out, "You'll notice I'm much higher functioning than the others around here. There's no one here that I want to even go out with." That may well have been the case, but he had already been through more than a few sexual partners at the clinic. He wasn't bitter about it, he insisted, but it hardly seemed like he had resigned from the dating scene entirely. The whole thing was confusing to him, why and how things just don't work out. He mused, "Um, I just know that I,

I just have holes in my brain [laughs]!” Leticia, a thirty-seven-year-old African American woman with a diagnosis of paranoid schizophrenia, made a habit of whizzing by what she viewed as the usual nonsense of people hanging around. She had a reputation for being “together”: she was well spoken, and she dressed neatly and smartly, with carefully applied red lipstick. She wasted no time getting to the women’s group to discuss what was on her mind. Not a casual “talker,” she still had plenty to say when problems arose. She was also known for giving good advice and indicated she felt she got a lot of support for family or logistical problems. She had had to move because her sister was bringing too many boyfriends around, when she herself was actively dealing with her own Catholic guilt about having had premarital sex (with a man she married and later divorced). She considered that as a source of the trouble she had keeping her mind “stable.” She simultaneously dismissed and entertained the possibility suggested to her by her family that the problem might have involved someone putting a spell on her. She was aware that following her divorce there had been jealousy on the part of the daughter of the man she was dating. But who knew? It could just as easily have been her ex-husband. She couldn’t spend much time thinking about it. She had a brother to see every day, along with her boyfriend. She needed to get to group and get out. Unlike a lot of the people at the clinic, she was busy.

We conducted in-depth semistructured interviews with every participant during which we asked about a range of topics, including medications. On the basis of previous studies, I designed the ethnographic interview, the Subjective Experience of Medication Interview (SEMI), to be conversational and to collect narrative data about daily routines and activities, current living situation, social life to include friends and dating, work or volunteer activities, and, later in the interview, the experience, practice, and effects of taking antipsychotic medications.<sup>16</sup> Tables 2 and 3 summarize the clinical and sociodemographic data collected for the ninety research participants.

Taken together, the ethnic composition of the study roughly reflected the adjacent suburban areas where the two community clinics were located, with a population composed of about three-fourths Euro-American and one-fourth African American. Both ethnic groups were from lower-middle-, middle-, and upper-middle-class families and on average were forty years of age and had been ill for over twenty years, usually with multiple hospitalizations. The vast majority were clinically considered “drug treatment refractory” insofar as first-generation anti-

TABLE 2 SOCIODEMOGRAPHIC CHARACTERISTICS OF RESEARCH PARTICIPANTS  
(*n* = 90)

	Number	Percent (%)
Gender		
Male	49	54.4
Female	41	45.6
Mean Years Education (SD)	13.0 (1.9)	
Mean Age (SD)	40.7 (7.9)	
Ethnicity		
European American	70	77.8
African American	20	22.2
Marital Status		
Single	76	84.4
Married/partner	5	5.6
Divorced/widowed/separated	9	10.0
Living Situation*		
Alone	23	25.6
Partner/spouse	9	10.0
Relative/parent	38	42.2
Roommate	5	5.6
Group home	15	16.7
Have Children		
Yes	16	17.8
No	74	82.2
Working Situation*		
Not working	54	60.0
Half-time or less (< 20 hours)	20	22.2
Half- to full-time (20+ hours)	16	17.8

\*Due to rounding, percent may not equal 100.

psychotic medications had not yielded satisfactory effects. For the study overall, about 60 percent (54 participants) frequented the university-affiliated outpatient site that had been initially organized as the Clozapine Clinic.<sup>17</sup> In an effort to obtain more participants than could be included in the first phase of the study, we recruited subjects from an additional community clinic across town. As shown in table 3, various kinds of atypical antipsychotics were taken by the research participants. Clozapine accounted for over half (57 percent), but other drugs (Risperdal, Zyprexa, and Seroquel) were also often prescribed. I reiterate that while the present research began by specializing in treatment using clozapine, that clinic and the second community clinic utilized by our research participants prescribed many kinds of second-generation drugs.

TABLE 3 CLINICAL CHARACTERISTICS OF RESEARCH PARTICIPANTS  
(*n* = 90)

	Number	Percent (%)
Diagnosis (SCID)		
Schizophrenia	73	81.1
Schizoaffective	17	18.9
Mean age at onset (SD)	20.6 (7.3)	
Mean years ill (SD)	20.1 (8.4)	
Mean admissions (SD)	7.0 (7.0)	
0	3 (3.3)	
1–5	46 (51.1)	
6–10	27 (30.0)	
11–15	5 (5.5)	
16–20	6 (6.6)	
21+	3 (3.3)	
Outpatient treatment*		
≤ 5 years	32	35.6
6–10 years	33	36.7
11–15 years	22	24.4
≥ 16 years	3	3.3
Current atypical antipsychotic**		
Clozaril/clozapine	51	56.7
Risperdal/risperidone	16	17.8
Zyprexa/olanzapine	15	16.7
Seroquel/quetiapine	6	6.7
Melperone	2	2.2

\* For length of treatment at current clinical site.

\*\* Due to rounding, percent may not equal 100.

### CHEMICAL IMBALANCE: THE MASTER TROPE

The principal ethnographic concern of the study was to understand the actual experience of the research participants. Given the fundamental importance of how people conceive of mental illness to define their experience and influence the course of their illness, it is important to have a sense of what kind of problem participants thought was involved and how it affected them. Of the ninety participants, fifty (55.5 percent) used the language of “chemical imbalance” to describe the problem. A smaller number, twelve (13.3 percent), said their problem was one of “stability.” Yet another third (31.1 percent) endorsed neither idea, citing a wide array of illness concepts. Speculation regarding likely causes of the problem revealed a high proportion of distinctly nonbiological

ones (society, supernatural or occult forces, traumatic events), but the ultimate effect of these causes was often a “chemical imbalance.” When it came to offering an explanation for how the illness works, once again and by far the most common articulation was metaphoric reference to “chemical imbalance.” A commonplace for over three decades now, this metaphor is invoked to refer to virtually any psychiatric diagnosis. Mental health professionals typically spoke to participants about their problem through reference to “chemical imbalance” as a presumptive brain-based disease. Given its fluidity of application, the cultural-clinical category of chemical imbalance serves as an odd-job category in a manner parallel to that of *nervios* (see chapter 3) as deployed by Mexican-descent families. These two broad cultural categories are, however, distinctively different in cultural meaning and consequence.

Comparing the Euro-American and African American narratives about their subjective sense and use of atypical antipsychotic medications revealed differences in ideas about the problem. Euro-Americans were more likely to speak in the language of chemical imbalances, while African Americans were relatively more concerned with bodily “stability” and “balance,” which has less to do with chemicals and more to do with social problems—often familial—that may or may not entail spiritual struggle or a magical spell. Ethnographic work with African American children diagnosed with pediatric bipolar or ADHD conditions by Carpenter-Song (2009a, 2009b) found that compared to Euro-Americans, African Americans were less likely to have a biomedicalized perspective on the problem. In the present study, comparing African American and Euro-American responses, the former tended not to elaborate on illness-related questions. Responses were often brief relative to other narrative data they freely offered. Analysis of the data suggests three possible interpretations of this. First, in this study African Americans eschewed commentaries on medical knowledge. In this respect, such a tendency is not dissimilar for many Euro-Americans; however, African Americans have a culturally distinct set of ideas emphasizing a different order of importance. Disavowing medical expertise, one individual was reluctant to speculate on his illness and medications, saying, “I’m not a doctor, by chance, so I couldn’t really say.” Second, the reluctance of many African Americans to elaborate on illness-related questions can be summarized in the notion of family or personal “business” (see also Carpenter-Song 2009b). Because illness is often deeply embedded in familial and interpersonal relationships, talking about illness may be viewed as revealing things that are, in the words of one individual,

“none of their business.” It may be viewed as inappropriate to air the “dirty laundry” of illness, especially to Euro-American interviewers, physicians, and others outside of the individual’s family or community. This hypothesis is substantiated in the narratives of several African Americans in the study. Third, in addition to either choosing not to discuss personal business or being encouraged not to do so, it is possible that African Americans do not elaborate illness narratives because illness is just one aspect of their lives among many with which they are currently dealing. As such, illness may not hold a privileged position in the way individuals thematize themselves. One African American woman, Mattie, put it like this:

I think I’m doing okay. I mean, I mean, it’s, I have to be, I gotta be. I mean, I gotta see that I have this mental illness, but still. I’m able to go on. Like I said, believe it or not, I do a lot of things. I mean, as far as help with my mother, help with my kids, or whatever . . . a good day for me . . . to function well, to take it, business is very important to me, you know. To take care of business. Business is, being able to, I don’t know the word, just taking care of business, you know. Make sure the bills are paid, all the time. Make sure this and that, everything’s been placed, that’s all.

Although chemical processes are a dominant theme overall, the category becomes less objective and more evidently an abstract cultural artifact when teased out. Of the fifty persons who used the language of chemical imbalance to describe the problem, forty elaborated on the meaning of chemical imbalance, invariably as a problem located within the brain. Often this involved some kind of chemical deficit (37.5 percent), abnormal levels of chemicals (37.5 percent), excess chemicals (15 percent), abnormal brain structure (12.5 percent), or “firing neurons” (5 percent). One person mentioned “juices in the brain,” and another mentioned “electro-physical” problems. Frequently embedded in these responses are intricate ethnopsychological models of the body, bodily and chemical processes, medication as a useful tool in the management of symptoms, chemistry as a form of magic, chemistry as it relates to subjective, lived experience, chemistry as a domain of specialized and authoritative knowledge, and bewilderment regarding how medications work and interact with the body.

The cultural conception of schizophrenia as a chemical imbalance serves as a master clinical trope in the United States to define and organize “a complex and unwieldy bit of reality into a simple and handy form” (Malinowski 1954: 35). This is significant given that there is evidence that cultural conceptions of mental illness play a role in shaping



how illness is experienced and how it is treated, as well as its course and outcome (WHO 1979; Jenkins 1988a, 1988b; Jenkins and Karno 1992; Hopper 2004). With respect to psychiatry as a culturally constituted therapeutic enterprise, the conception of mental illness as a problem of chemical imbalance operates as a key symbol that is “crucial to its distinctive organization” (Ortner 1973: 1338). As a key symbol, it performs an essential “work of culture” (Obeyesekere 1990) to signal the neurobiological mechanism of illness and to suggest the psychopharmacological strategy for its treatment. It is precisely its imprecision and openness to polyvalent interpretations that allows the cultural notion to accomplish this work and thus that appeals to patients, kin, and physicians as a symbolic interpretation of what the problem could be.

Since so much rests on the notion of balance and claims by pharmaceutical companies that taking their drug is the quickest route to regain it and since the metaphor has penetrated into the lived experience of those who take the drugs, it is worth emphasizing the sense in which the idea is cultural and metaphoric rather than empirically descriptive pathophysiological objectivity.<sup>18</sup> Indeed, what comes to mind is the relevance of Malinowski’s (1954) famous juxtaposition of magic, science, and religion as characteristic of contemporary society with respect to the place of psychopharmaceuticals, especially when we take into account the immediacy of lived experience. This is the case because the global prominence of biomedicine has neither banished nor rendered arcane the appeal of magic and religion as refracted through scientific knowledge in what I am here calling cultural chemistry. Along with analysis of cultural processes of the subjective experience of medications, the blurred conjunction of magic-science-religion can be applied to the analysis of pharmaceutical markets and global capitalism (Jenkins 2010a: 3). Pharmaceutical corporations deploy the lure of science, magic, and religion for economic gain by incorporating these cultural elements into advertising directed at customers (clinicians and clients/users/survivors), as well as public health campaigns.<sup>19</sup> This marketing is disseminated across economic strata and targeted at specific subgroups for ailments both serious and minor. It constitutes a complicated social field for the study of cultural chemistry that is usefully considered in relation to notions that I have formulated elsewhere as the pharmaceutical self and pharmaceutical imaginary (Jenkins 2010a, 2010b).<sup>20</sup>

Indeed, while chemicals and neurons might be involved, just how this could be was mysterious. Although the trope of chemical imbalance might initially seem an untroubled description and explanation of mental illness,

it is not only empty on existential grounds, but also as a matter of subjectivity. I have observed a profound struggle for interpretation as people try to understand a chemical imbalance of the brain and what psychotropic drugs are, what they do, and how they work. In sum, beyond the notion of chemical imbalance there is a remarkably imprecise and elusive quality of language and interpretation. As a matter of subjectivity, the pervasive ascription to patients of a chemical imbalance is so generalized and vague that the phrase is virtually a throwaway. It explains everything and nothing. More important, it does not take us to the actual experience of participants on medication, to the bodily feeling of chemical imbalance.

#### INCREMENTAL IMPROVEMENT AS SUBJECTIVE SELF-PROCESS

Against the background of these conceptions about the mechanisms of their illness, the vast majority (77.4 percent) of participants reported that they did experience a marked subjective sense of improvement. This was perceived precisely as a comparative and relative matter in light of biographical histories of symptomatic severity and suffering, on the one hand, and previous medications they had taken, on the other. It is significant that the majority of participants are quite clear if not emphatic that their conditions had improved. As significant as that observation is, so too is attention to the temporal dimension of the process as incremental and nonlinear but no less subjectively discernible. This central finding of the study must be borne in mind as we interrogate clinical and media claims of immediate and dramatic results. The appeal of instant and clear-cut results as opposed to those that are gradual and complex has more to do with the cultural orientation of American science and medicine than the trajectories of lived experience (see M. Good 1995, 2011). Americans are not typically fond of incremental results and far prefer—in this case certainly—the appeal of the “big and bold.” In fact, however, when medication led to gradual improvement over time, participants saw the need to take it regularly. This was the rationale one man gave for taking his medication “religiously.” Definitive reports of improvement were given by most people in the study and were not significantly related to variations in clinical or sociodemographic characteristics. However, while the majority of participants insisted on the importance of regularly taking their medications, the African Americans exhibited a numerically greater tendency to attribute their improvement explicitly to medications.

Although their effect may be incremental, the new generation of drugs has clearly been transformative for some study participants. They described definite and striking phenomenological differences as a result of taking or switching to atypical antipsychotics. Individuals commonly framed such differences in a before-and-after narrative structure. “Before,” according to this scenario, refers either to before the onset of illness or to a period of time on previous medications. “After,” in all cases, refers to after taking or switching to atypicals. In the case of thirty-two-year-old Brad, who received treatment at the Clozapine Clinic, it was transformative. During an interview, I asked him how things had been for him prior to taking Clozaril.

*Brad:* It’s unmitigated suffering.

*JJ:* Unmitigated suffering?

*Brad:* Yes.

*JJ:* In what respect? Could you say a little bit more about that?

*Brad:* Well, I often allude to what the soldiers had to go through in the trenches, uh, during World War I. They’re, they’re, when dealing with this illness, there’s almost an aspect of horror to it. It’s very merciless. It’s very cruel. I hope that doesn’t sound like hyperbole or anything. Well, I think that, I think that it’s because, in some respects, it’s incommunicable. It’s, um, something that, *if you haven’t lived through it, you can’t quite completely fathom it.* That’s the way it was for the soldiers back in World War I. They could never quite really convey, for those who were on the home front, really, just, the horrors of the day-to-day sensations that they had in the trenches. Um, uh, in the moonscape, where everything is turned upside down, and where perception is, um, very, um, what’s the word that could I, I could use, perception is all topsy-turvy and, um, and mercy is elusive.

This young Euro-American man called the effects of clozapine “liberating” and was pleased that he had more energy to invest in “things other than the illness.” He further described the effect of the medication as “serenity” and noted that in terms of social relations his “bitterness, anger, and intolerance” were gone overnight. He described other effects as gradual, occurring over a period of six months.

Brad was convinced that clozapine had done nothing less than saved his life. At the same time he reported with some hesitance problems associated with this salvation: the medication made him feel depressed, isolated, and prone to overeating. Yet he qualified these comments by noting that he didn’t really know if these were medication-related effects since he was “not a doctor.” Another participant, David, recalled,

“I wrote this one poem saying that when I’d gone psychotic, the agony and the suffering would make Christ look like a teenage girl in bobby socks and saddle shoes and the Catholic girl skirt with white blouse sitting at the drugstore fountain.”

While the NIMH Clinical Antipsychotic Trials of Intervention Effectiveness (CATIE) study found little difference in symptom improvement when comparing older and newer antipsychotics (Lieberman and Stroup 2011), the SEACORA data do not support this conclusion. This may be accounted for in part by the fact that as a group the participants in our study regularly took their medication while the CATIE participants had typically discontinued theirs. Moreover, as a group our research participants had been “treatment refractory” for typical antipsychotics, and the CATIE researcher noted that clozapine was most effective for those whose symptoms did not improve with first-line treatment. Another factor that must be taken into account is that whereas the CATIE study did not investigate the subjective experience of medications, this is the central concern of SEACORA. Based on our data for persons living with persistent psychosis for nearly two decades, the majority reported the definitive perception that the atypical antipsychotic drugs contributed to significant improvement. They were clear that, relatively speaking, things were better. At the same time, however, numerous inadequacies were apparent. I examine these further below.

#### MIRACLE DRUG OR AN “AWAKENING”?

It is possible to describe more precisely the extent of the participants’ perceived changes and whether they endorsed the idea that specific terms like “miracle drug” applied to their situation. Over half (54.5 percent) of the participants endorsed the idea that the antipsychotic they were taking was a “miracle drug,” either spontaneously or in response to a specific question. Surprisingly, given the saturation of a clinical ideology of and discourse about the drug’s efficacy that characterized the ethos of the Clozapine Clinic, this endorsement did not vary between the two clinics in which we were working.<sup>21</sup> Nor did gender or ethnic differences matter. However, there were slight differences in relation to the type of antipsychotic drug used. Clozapine users were most likely to think of the drug as a miracle (56.9 percent), followed by those who took Risperdal (53.3 percent), Zyprexa/olanzapine (46.7 percent), and Seroquel/quetiapine (42.9 percent).

Several examples give a sense of those who affirmed, were equivocal about, or disavowed their medication as a miracle drug. One woman was emphatic: “Clozapine is a miracle drug.” And another said:

Seroquel is a miracle drug. To stop the voices. That’s a miracle to me . . . that started with me with the Zoloft. It was just like, um, one day I just got up and it’s like the first thing I noticed was the birds chirping. And I was, like, it just hit me like a ton of bricks. It was the most beautiful sound I ever heard. And I just sat there and started crying, going, thank you, God. You know, I, I just appreciated the birds chirping. And it was another day, a brand new day. It just felt like a cloud had lifted. That’s the only way I can explain it. It’s just like a, it was like a total change, like *zvoot* [makes noise] you know. Like from night to day, it was just like a cloud lifted over me . . . then I knew I was starting on the right road.

An example of a more measured response to their medication as “possibly” a miracle drug is as follows:

Well, I think they’re on the right track. I think they’re making progress in getting a medication that will help a lot, you know. I think it’s gonna be a while before they get a couple medications that work for everybody. I think they’ll improve in the future. I’m looking forward to seeing what they come up with. ‘Cause they might find something that will improve my life quite a bit, and that’s the way I feel about it. I think they did the research . . . nobody wanted to give them any money for research or anything, and they stuck to it, and now they’ve made history. You know, they got on TV and the news and that. So I’m very encouraged by these medications.

Finally, I provide an example of the many (45.5 percent) who disavowed or were disaffected with the notion of their medication as a miracle drug.

Um, um, well, I don’t know. Um, I don’t know. I mean, you don’t feel like a miracle has happened and you’re cured and everything’s hunkydory . . . It’s not like, not like a miracle happened, you know, I still, I still have things to deal with, you know? . . . It’s not a miracle . . . I used to think that . . . Clozaril wasn’t doing any good, and the other medicine was the one that was doing the good. But somehow I want to believe what they’re saying, that the Clozaril remains an important drug, you know.

What about awakenings? We categorized participants as having experienced an “awakening” when, either in response to a direct interview question or spontaneously, they made a narrative statement during the primary research interview indicating that they had experienced a subjective sense of substantial and global transformation from a previous illness state. Only a quarter of participants (22, or 24.7 percent)

reported that they had experienced an “awakening” under this definition. There were no ethnic differences in response pattern, although there was variation in diagnostic subgroups, with persons diagnosed with schizoaffective illness significantly more likely than persons with schizophrenia to have experienced an awakening (Fisher’s exact,  $p < 0.03$ ). The phenomenological quality of awakenings differed as well, with eighteen of the twenty-two participants describing the experience as a profound transformation of reality. There were no gender differences. Below is a description of what we called a phenomenological type of awakening, though the sense of profound transformation of reality for the better was not long lasting.

It’s kind of hard. It’s like trying to describe the color blue to someone who has never had sight. You know what blue is, but you don’t know how to say it to make them understand. . . . I just know that I’m benefiting from the way I am now versus the way I was before . . . now I know what reality is.

Finally, less common was a “social” awakening that we defined as having experienced highly significant positive transformation of social relations. Only four of twenty-two participants reported an awakening of this social sort, and, interestingly, all four were female. This is too small a number to conclude that women were more oriented to sociality to begin with, but the data are suggestive in this respect.

#### ARTICULATING MEDICATION EXPERIENCE

Most studies would stop at this point rather than penetrate to an understanding of medication experience as an existential totality in the experiential immediacy and intimacy of everyday life. Our data allow us to enter precisely this remarkable and sometimes surprising domain, reconstructing it across the experience of our ninety participants with the sense of mapping uncharted territory. I attend to the manner in which medication is reported by persons to transform the way they are oriented in the world, to themselves, and to others, which I refer to as orientation self-processes. As evidence for these processes I focus on narrative elements in the ethnographic interviews, following the line in the social sciences according to which narrative is a methodological locus for understanding subjective experience and transformation of self in a cultural context (Bruner 1990; B. Good 1994; Kleinman 1988a; Peacock and Holland 1993; Sacks 1990; Mattingly 1998, 2010). I give particular attention to three salient narrative elements that emerge from

these data: (1) a series of experiential loci ranging from immediate bodily sensation to intersubjective settings of everyday life; (2) a series of frequently recurring and usually transitive verbs used to describe the action of medications and that can be organized into several groups; and (3) a description of medication experience along an expressive continuum between literal and metaphoric where the boundary between the two is often indistinct.

We have seen that in general participant explanations of how their illness works emphasize notions of balance and stability, with a locus in brain function and chemicals. With respect to how they talk about the medication's effects on them, responses tend to address both what it does and how it feels. Both explanatory and descriptive statements tend to have recourse to metaphor, though often the boundary between literal and metaphoric statements is not clearly defined. Although occasionally persons talk in terms of the "happy pills" that keep them out of the "looney bin," close examination of their language use discloses a far richer existential engagement with the medication and its effects. Some unconventional but revealing expressions occur as well, such as that mental side effects may be good while physical side effects may not be, with the meaning that from the mental side the drugs can ameliorate symptoms while from the physical side the drugs can cause unwanted and substantial weight gain.<sup>22</sup>

### *Bodily Sensation*

One of the first and most striking results of the study's inquiry into medication experience is the immediate bodily experience of the drugs, a feature often ignored in accounts of patient experience but a phenomenological bedrock of the self-processes initiated by atypical antipsychotics. The following excerpts provide a sense of the somatic feel of antipsychotics and how participants talk about the bodily experience of the perceived effects of medications.

*Vaughn:* Like a tingling feeling. Like my body starts to go to sleep before my head . . . I know when it's about to work . . . I can feel it working through my blood system . . . I think I told you before it was like THC so my tongue gets numb and feels like it's working through the legs. It's a tingling feeling.

*Alice:* Well, like I said, it clears up my head better. I think even emotionally, as much as I dislike it, I have to admit it does make me feel better mentally . . . It's like a freight train in your head [i.e., running powerfully along the tracks], like your head's screwed on right.

*Joyce:* Well, it makes you feel numb in your brain. Your brain goes numb but that could be from the chemical imbalance. It gives your body a kind of numbing feeling . . . It numbs my brain so I can think. It numbs your body.

*Louise:* [It's hard to] get used to—my mind being normal sometimes. Like night and day. It's a relief that I have a mind released when it was all tied up in knots. Um, it's like an orgasm. It really is. It's a release. Except it's up here [points to head].

*Sally:* I feel like I have a different body for every drug I've been on.

Unelaborated as it may be, the experience of having different bodies for different drugs cannot be regarded as peripheral to the medication experience if our goal is to understand it as an existential totality. Likewise, vivid and explicit analogies of the somatic experience as akin to an orgasm in the head or like a freight train in the head must be taken seriously. Both describe a sensation of surging within the head, in one instance experienced as a powerful release and in the other as a powerful sense of moving forward “on track” rather than in a scattered, confused, distracted manner. The sensations of tingling and numbing both in the brain and elsewhere in one's body such as the legs or bloodstream concretely indicate that the medication is working. Perhaps most striking is the apparently contradictory statement that the medication “numbs my brain so I can think,” where rather than numbness being associated with diminished thought processes, it neutralizes an alienated and uncontrolled brain, thereby allowing one's rational self room to assert its capacity for thought.

### *Toxicity*

In another kind of medication experience, the corporal and the cognitive are in close association under the sign of toxicity in the verbs *to poison*, *to be doped up*, *to be tranquilized* or *knocked out*, or *taking “gasoline.”* Also evident is the fear of being addicted, in the sense of a narcotic, or of being dependent, in the sense of needing to take it indefinitely—not unrelated concerns from the standpoint of daily life.

*Jake:* I may skip the morning or afternoon once or twice or three times a week. To kind of clear my system out. Or to clear some of the toxicity out or something, with the drugs and my biochemistry and stuff.

*Ruby:* I'm afraid my brain might be poisoned or something. . . . Sometimes I'm afraid of chemicals and all that stuff about poisoning people . . . but I take the medicine anyway. . . . my friend thinks it's real bad for us and



that we become poisoned or whatever . . . sometimes I worry about the chemicals and stuff like that in your brain, and I just pray about the neurotransmitters and all that.

*Ronald:* What it basically does, it allows me to flush my inner system and allows me to wake up for the next day . . . but I'm able to flush my system and wake up and things, so it also flushes my inner system. . . . And always being tranquilized and knocked out with medicines and having people around me trying to figure me out, you know. And they can pump their drugs or drill me . . . I reverse the effects when they think like they're going to use their technologies, like you know X-ray juices through the wall, or drugs coming in and agitating. . . . Even though they want to drug me and make me witness, that's not in my life, because that's all hallucination.

*Kirsten:* Well, if I miss a dose maybe I'll start to feel a little bit, you know, that I need the medicine, but I don't want to be addicted to it either. . . . Well, sometimes I feel like I have to have it. But I don't feel like it's, you know, like you know people who are taking crack and drugs so they feel they have to have their, you know. . . . Sometimes I worry about the side effects, but I was just wondering [whether] the chemicals in the medicine, can that really affect your system or your immune system or anything?

*Mattie:* I'm glad I don't have to take anything that got me drugged. I don't want to be on drugs. . . . One day I hope that medicine is improving over the years, like I said, medicine years ago, they drugged you. They literally drugged you. This medicine now, they come where you can get alert and you're not—you know, you're real alert.

*Derek:* Worries or fears about medication? I'm afraid I might become addicted and I might need it for the rest of my life.

*Felix:* Oh, I'm kind of dumb on clozapine. If you try to figure out what time it will be five hours from now it will take me a minute or two and I might even have to use a pencil and paper because it's more difficult to put things together. But it's okay because I'm not in any trouble where I need to put things together anyway.

*Valerie:* I think I'm taking enough meds as it is. But absolutely, I don't know how I would be without it. They tried me on Depakote before the Seroquel. That stuff almost killed me. It was like I was OD-ing on it. And I couldn't get out of bed. My voice got totally slurred. My speech was totally slurred. I felt like I was slowing down. It was a terrible feeling. So I stopped, because this one day I went, "This is not right. My body is limp like a ragdoll. Something is not right." So I stopped taking it . . . the best part is, the medication they have me on now, none of it is addictive. It's short acting in your system, like if I need to be taken off it, I really like that . . . I don't like the thought of being on something that I can be addicted to.

*Enoch:* You might want to try some other medications, because it [Clozaril] does attack you when you first start using it. It makes you feel strange . . . not altogether there, kinda.

Skipping doses or stopping the medication altogether is sometimes done explicitly to clear or flush the drug out of one's system and implicitly to maintain some control over what one puts into one's body. A sometimes palpable ambivalence about one's need for the drug stands out in many of these remarks, and this will become even more evident when I discuss the social lives of medications below. Yet for the most part the atypical antipsychotics come across better in this respect than typical ones, including Loxitane, Thorazine, Haldol, or the antidepressant Prozac.

### *Thought Processes*

The intimate connection between bodily experience and mental presence implied in comments such as that medication “numbs my brain so I can think” and concerns about poisoning and addiction bring to the fore the narrative deployment of verbs that describe the effect of medication on orientation to one's own thought process. The next group of verbs to which I will call attention refers to how the medication “straightens,” or “clears.” The following statements are typical.

*Amelia:* I get psychotic is what they call it. I call it just a clear head. I see things clearer, I see myself as Christ figures. They say, you're crazy, man.

*Daria:* It [medication] straightens up, it's supposed to straighten up the thoughts.

*Mattie:* I feel, uh, clear headed. . . . What I go through, it's confusing. I have, uh, confusion and different things, but what I'm saying is clear headed. . . . It's just the best way I can explain it is clear headed, I'm alert, I'm alert.

*Valerie:* You know, I'm just clearer. Back in the real world, so to speak. Which I'm very grateful for . . . when I basically wasn't really functioning well, I was just kind of like there. Not really listening to the conversation, nothing was sinking in. I was kind of in a fog so to speak.

*Bertha:* It keeps me together and helps my thinking, my bad thoughts. It seems like it works on my mind. Like it holds it together.

*Paul:* It really helps me have clear thinking. They told me this will help me have clear thinking. And I thought, how can a pill make your thoughts clearer? But now I understand.

Associating the psychotic state itself with clarity of mind is not common in this group, among whom symptoms were more or less successfully controlled. Thoughts that are straight, clear, and alert or that allow one to be in “the real world” stand out in these passages, in contrast to confusion and fog. The one outlier in this group of comments invokes

coherence in the sense of holding the mind together and suppressing bad thoughts, but it is not much of a stretch to connect this kind of coherence with mental clarity.

In another category of effect related to thought and mental activity, the relevant verbs are that medication “mellows” or “slows” like a “mental anesthetic.”

*Amelia:* I used to go in spinning states. I don't have those as often . . . you just kind of spin in your head and your brain, and your brain races, but it can't do anything.

*Alice:* It slows my head down. The medicine slows you down. Like I can't concentrate for anything, but the clozapine numbs you mentally, it's like a mental anesthetic. But the doctor told me the reason I gained weight is because it doesn't only slow your head down, it slows you physically down too. It slows your entire body down. It slows your metabolism down. I ate more food then [before medication] than I do now, and I'm heavier now than I was then. . . . It slows my head down. It stops the bad voices from taking effect as much as they would. As much as they were.

*Joline:* In the sense that it slows everything down, so there's not as much pressure. I was at the store, and I started hearing all this noise around me, and I thought, “Oh no. Oh, thank God, I've got my medication.”

*James:* It kind of deadens me.

*Daria:* It helps the racing thoughts and helps me sleep and helps me to relax . . . I used to have racing thoughts and it helps that, I don't have those racing thoughts.

*Geoffrey:* I think they kind of keep my mind from racing. A lot of times it helps just to slow down and not try to do too much at once.

*Paul:* It will slow things down, so you're not racing, so you're not anxious that you're having thoughts come too quick and overlapping and everything.

The emphasis in these excerpts on clarity and velocity of thought does not imply that symptoms such as visual and auditory hallucinations are negligible by comparison. Nor does it suggest that the medication does not address the latter. I hypothesize instead that hallucinations are by definition ego-alien experiences and on some level less frightening and disturbing than confusion and the racing of what are unmistakably one's own thoughts. It is also possible that for these persons the current medication addresses their thought processes more observably or dramatically than was the case with their previous medications. While they mention concerns that the medication may poison their brain, have toxic side effects, or be addictive, by comparison effects of the older

generation of antipsychotics are far more often described as making one feel doped up or dopey, tranquilized, knocked for a loop, knocked out, in the ozone, or drugged.

### *Stability and Balance*

Beyond the effects of medication on immediate thought processes, we can identify a domain of utterances that is a degree more reflective, existential, and metaphoric. Among the relevant verbs are *regulates*, *smooths*, or *stabilizes*. These expressions are often related to the dominant metaphor of the illness as chemical imbalance, so that the effect of the drug is to establish or reestablish the balance. For example:

*Jerome:* I have a dead part in a part of my brain, so because of that dead part, I don't think normally . . . they [drugs] provide chemicals in your brain that will change your thinking . . . I think they are reacting with other chemicals in my brain to produce more of certain types or less of certain types.

*Katherine:* Well, I think I was born with it. They say you're really born with it, but the chemical imbalance doesn't show up till you're older. . . . Well, it [the drug] replaces the chemicals in the brain.

*Candace:* It's just like a chemical imbalance. I mean it's just like diabetes. You have to take your insulin and that's that . . . my brain doesn't make that chemical . . . I think it keeps some kind of chemical in my brain and it gets the chemicals working. . . . It's just they give me some kind of chemical that I need.

*Geoffrey:* I guess it works or affects the dopamine in the brain. And if the dopamine is at the wrong level, you can start having symptoms. So I guess it kind of regulates the dopamine in your brain.

*Thomas:* Well, I guess it changes your brain chemistry. I guess your brain chemistry is out of bounds, and it roughly, uh, reconfigurates it somehow.

*Delbert:* I don't know. I guess it, um, I guess it works with the juices that are in the brain, you know, the chemicals that are in the brain . . . maybe it, um, regulates it. Regulates those juices or maybe I might be lacking something. . . . Maybe lacking something that you're supposed to have, like, um, maybe like them endorphins in the brain or something like that.

*Karl:* I think what it does is, I think it interreacts with the chemistry of my brain, and there's like a balancing act going on.

However, in some instances the metaphor of balance is used not in reference to chemicals but in reference to experience, as in the following examples.

*Jordan:* It keeps me balanced. Like a scale, you know.

*Jane:* It smooths my mood.

*Katherine:* My moods have been pretty stable.

*Laszlo:* The more they put me on meds, the worse the seizures got, but I balanced it out with the new medication, Clozaril. . . . It's smoothed and controlled my microprocess . . . I get bewildered at times and the medication just does its function of keeping me back to the "s" word—stable.

*Mattie:* I know I'm mentally stable enough to get through life right now.

*Felix:* Sometimes it's almost like it can balance out, you know, as bad as the illness is, sometimes I feel pretty good.

*Ellen:* It ain't doin' nothing right now. I can't get level. Shit, I can't get level for NOTHIN'. 'Cause I'm not a level person right now. I'm too many peoples right now. I'm not level.

*Bertha:* It helps me to be stable. And when I don't take it, I can't function. I notice I need it. It keeps me stable.

*Nate:* Uh, stable—not better, but stable.

Closely related to the ideas of stability and balance insofar as these are states that need to be maintained are utterances defined by how medication "keeps" one in a steady state. Interesting in this respect is the verb *to keep*, which is multivalent in its referents. Most common is a variant of the articulation that it keeps the person stable, together, balanced like a scale, at the same level all day, busy or active, out of the hospital, from being depressed and anxious, from getting confused, from hearing voices, from being crazy. Others say that the medication keeps some kind of chemical in their brain, that it keeps their mind from racing or keeps everybody happy. Some participants described the effect as keeping their "head screwed on right" or "the mental disease indoors." Yet another person said, "[It] keeps me on top of my parents' kingdoms." When the primary verb employed to describe positive medication effects is *helps*, a common articulation was that it helps keep the person busy or active, that it helps keep up appearances, the apartment clean, or the person clean. Participants also stated that it helps with the hallucinations, helps have clear thinking, helps not to obsess (though it screws up the memory), or helps to function.

### *Control*

Given clozapine's association with control, it is unsurprising that participants often said that the medication keeps symptoms under control,

keeps the body controlled, or keeps one from lack of control. The verb *to control* itself may refer to one's life, one's thoughts, one's symptoms, or oneself. One participant said that medication "controls red blood cells in my mind." We also heard "God is in control" and "Illness has control of me." However, the notion of control was most often heard with reference to trying to identify the locus of agency.

*Jake:* I try to control my thinking and my emotions and my problems and stuff like that by acting and behaving and thinking as normally as possible, in normal society as most people do, you know what I mean, a large percentage of people do . . . I think maybe it is biochemical and maybe the medicine itself, the biochemical makeup of the medicine actually affects my body chemistry and helps me to control and discipline myself, so whether or not its changing behavior is due to medicine, or if it's due to some psychological effect, or it's due to both, I don't know. Might be the medicine acts as a placebo.

*Amelia:* I'm real, real scared to be without them [the medications]. I feel handicapped by the fact that I'm going to be miserable without them . . . I feel handicapped by the thought that I have to take them. And I'm trapped if I don't take them.

*Alice:* I was hurting everybody, and I couldn't control it. I couldn't control my feelings. Or my emotions. I couldn't control myself [before the clozapine]. If I didn't take my medicine I would be totally out of control. . . . Oh, yeah, you can control mental illness. You just got to take care of yourself. Good hygiene. You can't let yourself go. If you let yourself go, your mental illness won.

*Sarah:* Just control the illness, control the chemicals. It [medicine] controls the dopamine and the serotonin, chemicals in the brain. I'm not sure how they do it, but they just do that . . . I think the medication can control it. I think there are things you can do to help yourself, but I mean everything else is beyond your control. But I think it was something, that no matter what I would have done, it would have happened. Especially if it's genetic, 'cause that's something you have no control over. . . . It's made [my emotions] under control. I'm not hostile anymore.

*Thomas:* Well, like I said, I have coping strategies. Other than that, I don't have any control. I take my medication. See a doctor, things like that. Those affect the intensity of the experience at the particular time, that's all. To think well, maybe—I hope I don't lose control of myself, you know. So I just—usually it goes away after a while. I get up and say I got to go. I say excuse me. I try to be polite and all, while I'm sitting there going . . . yeah.

*Valerie:* If I could have, I would not have let it happen. I never even saw it coming. But it's not like I'm just lying around either. At a point, I was. I had no control over it. But now I'm doing everything I can to stay limber and active [to avoid weight gain] . . . I don't want a medicine to make you

feel like you're in the ozone layer. Like, I once went to the dentist and had to take this for the pain. I took it once, and I went, "Uh-uh." Because I know that I was not in control. That's what I don't like. And I guess that's what I'm kind of afraid of, you know. Some people take all sorts of drugs, and I don't know how they can maintain control.

*Karl:* I think it's under control now because of the medication. I think part of the Clozaril—I wasn't able to control it, even if I wanted to, I couldn't . . . and schizophrenia can control you. It gets you to do things a normal person wouldn't do. And I don't know how it is for you, but I know how it is for me with schizophrenia. I think it is beyond a person's control. I mean, if they could control it, then a lot of people that come down with it would not be coming down with it simply because they could control it, but you can't.

In these instances people struggled to situate themselves existentially within the complex constellation constituted by whether one can control and discipline oneself, whether the illness has control of one's life and behavior, whether the medication is controlling the illness, or whether the medication is helping one to control the symptoms and their consequences in everyday life.

### *Discipline and Accountability*

The discourse of control is closely associated with that of discipline and accountability. Participants say both that getting well requires self-discipline and that taking the medication is a way of disciplining oneself. The degree to which one can rely on medication in relation to one's own efforts and will to be well is more complex than this, however, including the possibility of relinquishing oneself to mental illness as if it were a form of temptation.

*Felicia:* I think maybe if I just decided not to mix myself up, by making a choice, I could either live a normal life or mess it up. I decided to mess it up, turn against the skies, you know, like Adam and Eve with the apple and stuff. They weren't supposed to, and they ate the apple, kind of what's happened to me, you know. . . . Sometimes I blame myself for my illness—I blame myself for confusing myself when I was little.

*Candace:* When I'm sick, no one can help me. I have to help myself. Well, there are people there to talk to you, but you got to be strong.

*Mattie:* And I gotta be able to maintain, so this medication gonna help me, I gotta help myself.

*Steven:* Well, a regular man, he's got stress, too. Working all day or whatever, but if you don't keep yourself busy on medication, it's just gonna

slow you down. Because the medication's working with you, but you help yourself by working a couple nights a week. It'll get the energy. This way you won't feel like you're a couch potato. But if you move yourself, your body fast enough, the medication will help you. I'm not telling you it's gonna make you high or anything like that, but your strength and your working, you know.

*Paul:* Clozaril makes it possible, but you do the work, you know, with the mental illness struggle.

*Karl:* And the one who blows it is yourself. Who blows that opportunity to be out? You can't blame anybody else. You can only blame yourself, and maybe attribute it to your disease a little bit. 'Cause that's what it is, you know, it's a disease. But you can't die from it.

### *Identity and "Normality"*

It is a short step from concerns with discipline, accountability, and responsibility to overt concern with self and identity (Whyte 2009). We encountered statements such as the following: "I feel like a new person" (Candace); "The whole thing is I am a different person from then" (Paul); "I'm all in one piece" (Enoch); "I'm still me" (Nate). Problems with identity can be associated with the illness, as in "I feel uncomfortable about myself and, you know, having mental problems" (Kirsten), or with medication effects, as in "I'm not quite myself—if I talk to Dr. R maybe he can cut my medication and I start doing like I used to, on the get-go" (Alyssa). Statements of identity can be quite generic and more or less directly confounded with effect of the illness.

*Jake:* I like being myself, okay. I like being the kind of person I am. That might be part of the illness . . . I consider myself an individual, but I think I have some unique qualities. I believe other people have unique qualities, but on the other hand, I think we also all have things in common as human beings.

Other identity statements are more explicitly connected with the effects of illness and/or medication.

*Clark:* I used to think I was other people beside myself, and now I don't have that problem.

*Geoffrey:* I felt like I was outside myself or something, looking at myself from the outside. Like I was outside, out of my mind—like myself but I was outside of myself. Like I was hearing voices and stuff. I didn't really know what to make about that one, just because there was something wrong with me or I was just bad, like I was possessed or something.



*Karl:* When I was on Navane, I felt like I had a different body for every drug I'd been on, and now I feel like I have my own body and my own mind. . . . Sometimes I feel like my old self. The self I lost years ago to schizophrenia.

The thematization of identity links up with a discourse of normality versus abnormality that while not exactly a preoccupation of most participants is often not far from the surface. Certainly the group therapy sessions we observed were dominated by discourse on psychopharmacology and primarily oriented to the elusive “normal.” This is true for psychotropics ranging from antipsychotics to sleep drugs, as Martin (2010) traces in the culturally peculiar search for “normal” sleep cycles. In our study, the majority (64, or 71.1 percent) invoked the notion of normality at some point in their interviews. Exceedingly rare was the sentiment, “Sometimes I think I don’t know what’s wrong with being psychotic. . . . Sometimes I think I don’t know why people think psychotic is so wrong” (Amelia). Indeed, underlying the romanticization of schizophrenia in popular culture is the presumption that the normal is fundamentally boring. From the standpoint of the suffering inherent in the illness experience, normality is by contrast a value and an aspiration for everyday life, or at least a taken for granted baseline of the way things are, have been, or could be.

*Jake:* I just try to act normal behavior, think normal, feel normal. Not just go through the motions of being normal but live normal, as much as I can . . . so it’s not just a matter of going through the motion, or just acting—that could be a beginning—but it’s actually being as normal as possible.

*Thomas:* Well, I’m interested in what normal people think about—how they view things, you know. I’m very reluctant to get involved with a bipolar since I had that bipolar girlfriend. They can bring a lot of trouble, and I guess I’m more comfortable around normal people than other mentally ill people, except for ones I’ve known a while. But in general, I think I’m just as bigoted as anyone else about mentally ill people.

There is a recognition of not being normal, sometimes with the sense that the person was not aware of being abnormal prior to entering treatment (isn’t it normal to talk to oneself, or to hear voices?), as well as of having to act normal in certain situations and this being more or less of a strain. It is in this context that we must understand the following statements about medication and normality.

*Kirsten:* I’m not envious, I just wish I had a normal kind of background . . . I wish I wouldn’t have to take it. I wish I could just have a normal life. . . . You know, I get depressed, I feel that if my life was different, if I had a normal life like everyone else, I would not focus so much on the illness.

*Shirley:* I think I'm pretty normal. Luckily, you know, doing the medication, going to work, and going to school, and functioning like a normal person and everything. I feel pretty normal. I really do.

*Reginald:* Like, I feel normal taking it . . . I just can't think normally, like you want to feel normal but you can't really help yourself.

*Jerome:* Well, I know I have to take it to feel normal now . . . I [also] smoke cigarettes and drink coffee to feel normal. Well, because I need the nicotine and caffeine to feel normal.

*Katherine:* It's by far the best medicine I've ever been on. It makes you the most realistic. Even when I was on the Trilafon I would look in the past and say, "How could I have a mental illness because I was always so normal?," but on the clozapine I can look back and see how sick I used to be . . . I just feel more normal on the clozapine.

*Candace:* Keeps me not crazy, actually. Not weird, I mean, it makes me healthy. . . . It also made me gain a lot of weight, but be *crazy or fat. I choose fat.*

*Mattie:* I mean, in other words, I know I have a mental illness, but it's [medication] making me feel somewhat sane. Because normally what's in me stays in me because I can't talk to nobody about what goes on with me, because they would judge me.

*Bertha:* And then he said that I was doing good for me to be on my medication. I didn't seem like I was a mental patient or nothing like that, he said I have plenty of sense and that made me feel good, because people want me to think that I'm crazy but I'm not crazy. I know what I be seeing because I have mental illness, that don't mean that I'm crazy . . . [I want the medication to] make me stay stable and feel normal . . . make me back to normal.

*Nate:* It returns to feeling normal. Without the medication there's like, for a better word I'd choose "darkness," like a darkness of the mind and the medicine drives it off, gets rid of it—I might not be describing this real well, but that's my best.

### *Everyday Life*

Finally, one step beyond the overt concern with normality, we encountered articulations that described medication effects in everyday life in vivid and often poignant terms.

*Felix:* The clozapine has changed my mind many times. I'll be having a bad day and I'll come home and I'll have everything else completely fine. And I like that, you know—that it's not 5:30 and I'm still complaining about something that happened at 11:00. Or I wake up the next day still thinking that I had an awful day yesterday. The clozapine helps a lot. I just take it every day and I'm not having nearly as many problems with noises as I used to. It used to be one horrible symphony of annoying sounds.

And It's broken up now into little bits. You can deal with it a little bit at a time. And it's quieter.

*Ellen:* I got to find myself again, 'cause right now, I'm lost. Okay? But see, I know something goin' to happen, but right now, I'm lost. Like I say, them ambitions and things that I expect to want to do, right now, see, I lost that. No, I don't have that mood right now. I'm just goin' with the flow and whatever. I'm lost right now, but somethin' is gonna happen. I don't know when, I don't know how. But right now, just standin' nowhere, just lettin' these days go.

*Enoch:* Well, see, when I ran out of pills to take, I didn't sleep at *all*. I was up all around the clock for a couple of days. Then I tried to walk over the footprints in the sand, I barely made it back [to normality].

*Karl:* I like to say that the Clozaril is a mental dam that stops the flow of schizophrenia. The hallucinations are very seldom now. The paranoia is weakening considerably. I'm not really delusional in my thinking. I think my thoughts are more in line with reality. I am not raging out at people, accusing them of things. I'm not that loner anymore, walking the city streets, living on the streets . . . I couldn't forget on my own. By an act of my own law, I couldn't forget. But Clozaril has helped me forget the misery of the past. The craziness of it. Honestly, I don't think about it. And even if I tried to think about it, I couldn't remember how it was back then. . . . Some of the major things I can remember, but you know ten years ago I might have still been living in my mind. Now, ten years later, it's not living in my mind anymore. It's kind of like it died. It's like the memory died. It's not there anymore.

Two points are critical to understanding the domain of medication experiences defined by the kinds of responses considered here. In 1984 the anthropologist Lorna Rhodes published an article about the medication experience of psychiatric patients. Her exposition was framed in terms of the metaphors people used to describe their psychotic experience. She organized these metaphors into categories: blockage/release, clearance/fogging, distortion/straightening, poison/nurturance, breakage/remediation, and immobility/mobility. Our data include similar metaphorical expressions, with the difference that neither breakage/remediation nor immobility/mobility were prominent domains for us, whereas balance/imbalance and slowing/racing were relatively clearly elaborated. Given the twenty-year gap between these studies, it would be interesting to know if these differences corresponded to a difference between the first-generation antipsychotics in use at the time of Rhodes's work and the second-generation drugs taken by our study participants. Unfortunately, to determine that would require analysis of both sets of data, as well as some means of taking into account differences in social

characteristics and regional background among participants, the effect of the clinical ideology of biopsychiatry<sup>23</sup> that became consolidated in the interim and is likely to have effects on the discourse of medication experience in subtler ways than the obvious trope of chemical imbalance, and changes in expressive conventions among research participants and in the cultural milieu during the twenty years between studies. As for the metaphors themselves, what is evident from the research data is that often they are what might be called closely held metaphors in the sense that the usage is close to literal. Thus “it clears my head” or “it stops my mind from racing” is more readily understood as literal, as opposed to “it clears the fog from my head” or “it stops the runaway stagecoach in my mind.” Likewise, occasional metaphors such as clozapine as a dam holding back the flow of schizophrenia or a freight train running through the brain are phenomenologically vivid but not deeply constitutive of a discourse of medication experience.

Further, I have chosen to understand the material on medication experience in terms of a discourse that integrates the use of metaphors with the deployment of verbs describing the action of drugs and to highlight the elaboration of substantive themes at several levels of analysis. To summarize, these themes are bodily sensation, toxicity, clarity and velocity of thought, balance, control, discipline, identity, normality, and daily life. My point is that these are not to be understood as a series of discrete themes or topics but as an existential totality weaving together interrelated levels of meaning and experience. At each of these levels medication experience is intertwined with orientational processes that taken together define the self and one’s transformed place in the world. Bodily sensation produced by the medication and apprehension about poisoning and addiction are palpable and indeed inside one’s skin. Concerns with clarity and velocity of thought are subjectively immediate, perhaps invoking descriptive metaphors but without need for interpretation. Balance is both an interpretive concept and a feeling, a metaphor in which the notion of physical vertigo extends to both an effort to understand the cause of illness and a disrupted subjectivity. Control encompasses the self insofar as it is one’s self that is out of control and struggles for control, on one’s own behalf and/or with the assistance of medication. Discipline is a means of control that can be embraced or abandoned. It can be expressed as the discipline of thoughts, emotions, actions, and symptoms but also as the discipline of adhering to a medication regimen. Identity is in part contingent on control and discipline, because it is not only being/becoming someone or

remembering who one is, but more particularly being a person with mental illness and faced by its stigma. Identity is also a fully social and intersubjective issue and hence raises the concern with normality as simultaneously a problem, a standard, and a value specifically having to do with living among and in relation to other people. Finally, normality faces its tests and challenges in the kind of instances recounted in the final set of excerpts that open on moments of everyday life where possibilities are realized or foreclosed in ways unforeseeable by those who are not afflicted. Thought process, self, and social life are all represented in the discourse of medication experience, each element in relation to all the others and with profound consequences for existential coherence and the possibility for a meaningful life where the suffering of psychosis is held in check.

#### SOCIAL RELATIONSHIP TO MEDICATION: SELF-PROCESSES OF ATTACHMENT AND ANIMATION

While our data on the ways in which people experience their medication were surprising insofar as they constituted emergent evidence of an existential totality of self-processes, it should perhaps come as no surprise that persons also develop what can properly be conceived as a social relationship with their medication. The “odd couple” social relationships created by regularly taking medication provide yet another frame for the specification of distinctly cultural dimensions of psychopharmacology. Whyte, Van der Geest, and Hardon (2003) have formulated the materiality of medicine (*materia medica*) in terms of the “social lives” of medicines with respect to their uses and consequences. In their view, the *materia medica* that should be currently of greatest anthropological concern are commercially manufactured drugs produced by pharmaceutical companies and disseminated to every part of the globe. Besides the intended bodily effects, they note that pharmaceutical medicines have effects that entail nothing less than changing “minds and situations and modes of understanding” (3–4). The strong version of this argument is that medicines, as material things, have “social lives” in the sense that things and people mutually constitute one another (Appadurai 1988).

#### *Anthropomorphosis and Personification of Medications*

The anthropomorphosis of both psychotropic drugs and psychiatric disease is widely promoted in psychopharmacological advertising. The

well-known Zoloft blob has been reproduced as an utterly bland yet rhetorically powerful embodied representation. How can a disease or a pill “be” (or be like) a (nondescript) person? But these generics have a face, changeable emotions, and capacity for movement. The antidepressant Zoloft blob is well-known as a nondescript entity with “eyes” that morphs from unhappy to happy, advertised to combat a “chemical imbalance”: “When you know more about what’s wrong, you can help make it right.”<sup>24</sup> The television and magazine advertisements for the antipsychotic Abilify (ariprazole) by Bristol-Myers Squibb (marketed by Otsuka Pharmaceuticals America) have taken the anthropomorphizing of psychotropics a step further by marketing the product to capture the market for depression as an “adjunctive therapy” when an antidepressant alone is “not enough.” Having tracked pharmaceutical marketing campaigns for some time, I was struck by the ubiquity of these ads as a particularly disturbing development. Depression is anthropomorphized as a dark blue blob-being following (virtually stalking) a woman as she makes her domestic rounds to care for her house and family.<sup>25</sup> She has an ever-present relationship with this personified being that is configured primarily as a power struggle over “who” is in charge: the woman or “her depression.” The narrative accompanying the ad repetitively speaks in the possessive case, “my depression.” The boundary between person and illness is murky, but it is clear they live together in uneasy tension in which the drug (which in other Abilify ads is also personified as a powerful being) intervenes to draw the line for “who’s in charge.”

### *Self, Medication, and Illness*

Narrative analysis of data from the SEACORA project suggests a complex conjunction of subjectivity among the self, the medication, and the illness, with overlap and indeterminacy such that sites are fluid and inef-fable. This *mélange* is illustrated in figure 1. Figure 2 is an illustration of factors that participants perceived as critical in processes of improvement.

The “power” and “agency” of the medication not only “lies in person’s perceptions of these qualities as resident within a given medication,” as Whyte and colleagues empirically identify; it also is a quality of intimacy between persons and medications. Here another set of key verbs becomes relevant, including *reassure*, *show*, *like*, *give*, and *quiet*. For example, a thirty-two-year-old Euro-American man, Ronald, speaks of his medication as a knowing presence and refers to the medication as the arbiter of reality.

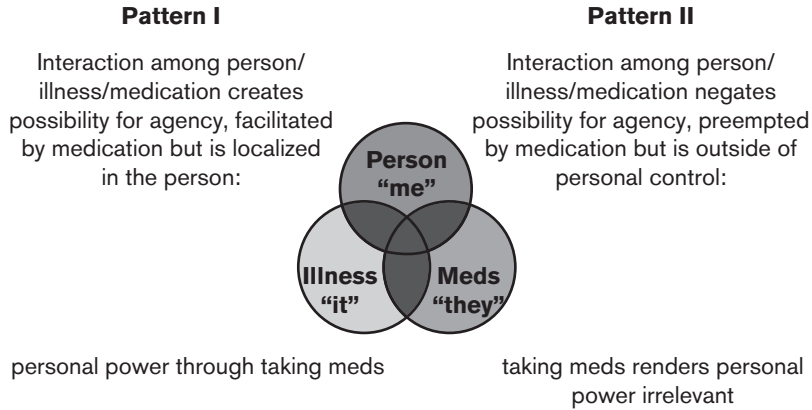


FIGURE 1. Experiential mélange of person-illness-meds.

It [medication] reassures me. . . . It shows me that reality is indoors. When you go outdoors that's even a more burst of reality. But like if I'm laying down thinking I'm fighting this and that and I've got the front lines for the civil war and I'm loading cannons and I'm doing crazy things in Korea or Nam. And it . . . this is dead, hallucinations. It's not real [laughs] . . . Indoors means it's a happier place. Because outdoors can be very unbearable, to the death, you know.

In another instance, a forty-year-old woman, Alice, taking Clozaril feared “bad effects” such as agranulocytosis. She imagined that an “attack” could occur if “it [medication] doesn't like you anymore.” People taking antipsychotics also described the effects as enabling them to interact socially, particularly with their families, in ways they otherwise could not. One person described this as the medication calibrating “spells” he would have in which he would “think negatively, like I'm dying or I'm going to. You'll have spells like that . . . and this medicine and stuff leads to one thing: family business” (Delbert). For him the critical feature of the medication was that it helped to differentiate “the ones you really should be with” from the ones (hallucinatory or not) who mean no good. Medication was an arbiter of the social and moral status of persons, pointing to who one should attend to or disregard.

### *Supernatural and Magical*

In some cases the social dimensions may be embedded in supernatural or magical forms of transformation. A forty-one-year-old African

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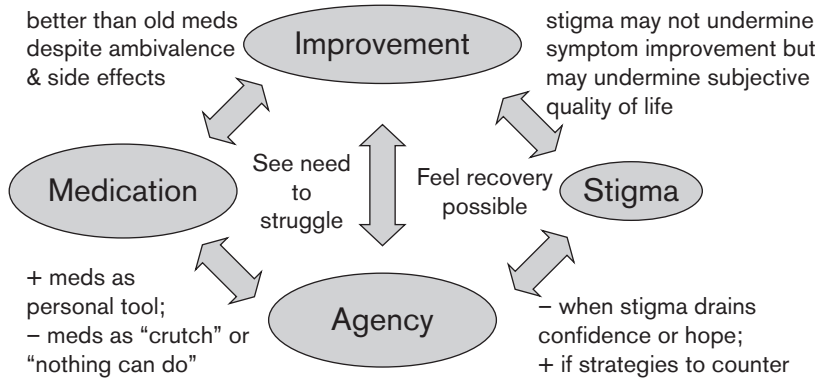


FIGURE 2. Relationship among factors perceived as critical to improvement.

American woman, Ruby, was as tenacious in taking her medication as she was unmovable in her stance that her trouble was not really “schizophrenia,” as her doctor indicated, but a satanic “hex” placed on her by her stepfather, in collaboration with her mother, when she was a small child.

They say they got the power to do that from my mother. She’s with Satan. She, um, had me by her boyfriend, and from what I understand, my stepfather or her husband got real upset because she had gotten pregnant by another man. So he told her that he was gonna put “triple six” on her. And she said, “If I were you, I’d put it on that baby I’m carryin’.” Said, “Cause you don’t want to go through what I’m gonna put you through.” So she got on his side and together they ostracized me and put me, you know, they put me in a—a—foster home when I was born. An orphanage home. And he went out and got two other girls pregnant. And he told her—he said, “now, we even.” He called me a bastard and dummy and stuff like that . . . there’s different ways people say about doing black magic. Different kinds. White magic. Black magic. Different types. Yourself or to cause harm to somebody. They all [involve] Satan.

During the course of this interview, two sessions of an hour and a half each, Ruby let me know that she had “discovered” that the medication “got the power” to quiet the demons stirred up by the “666s.” So, she said, “I never forget about [taking] it.” For her, it was the way to make things “even.” She was aware that her psychiatrist did not put much stock in her theory and told me she had decided it was best not to spend much time talking to him because he didn’t “get it, he don’t know better.” For his part, the psychiatrist remarked to me once in the clinic



hallway that this woman was a “good candidate” for atypical antipsychotic medication because she “takes it even though she doesn’t have good insight. Normally that wouldn’t happen. You don’t see it. But in this case I think she’ll stay [on the treatment regimen].” This physician statement implies that if he were to equate “lack of insight” to “lack of compliance,” then the clinical logic would be to use a different medication (possibly a depot injectable antipsychotic) or to hold different clinical expectations regarding the likely course of treatment.

Other participants integrated the social qualities of taking medication into their relation with a monotheistic god or demon. Ruby, for example, added during her interview, “I just pray about the neurotransmitters and all that. I know it seems kind of stupid, but . . . ” Mattie reported that she prayed to God daily that she “can keep medication.” She understood the fact that she was able to maintain a regular supply as an affirmative response to her prayers, saying, “God looking out for me.” Valerie was convinced that medication was a miracle directly attributable to God for which she also gave daily thanks. A male participant, Samuel, prayed for the “spell” placed on him to be broken and felt that his prayers succeeded both because of the medication and because of his active involvement in prayer: “I pray and when I wake up, it’s gone . . . the spell is gone.” Ketherine noted a change of heart; first, she said, “I thought I was demonically possessed,” but she eventually came to the realization that the combination of good friends and her medication had “broken” the possession, reasons she cited for staying closely aligned with both. In such cases, God becomes a fourth element folded into the intimate self-medication-illness relationship.

### *Interiorization of the Clinic*

A final relational quality of medication is “interiorization of the clinic”—a kind of societal embodiment that involves not only the ingestion of medication but also the incorporation of the clinical ideology as transmitted by doctors, other service providers, and the myriad social actors who claim moral and working knowledge of mental illness and its treatment. In this context the medication is a kind of benefactor in the sense that, as Kirsten put it, “They say that it [medication/Clozaril] gives your life back to you. . . . [And] I feel like that.” This effect is possible in part because, though unimaginable a few decades ago, the primary referent in psychiatric and psychological language for therapy has moved from “psychotherapy” to “pharmacotherapy” as the latter has become

preeminent in terms of sheer frequency of “treatments” actually offered. Previously, no matter what the modality (psychoanalytic, psychodynamic, cognitive-behavioral, etc.), psychotherapy has always been practiced and understood as interpersonal. Now the term *pharmacotherapy* is widely employed *as if* prescribing psychotropic medication were on a par with psychotherapy. While clearly symptoms must be elicited and monitored and prescriptions must be called in to pharmacies, what happens as a social matter of engagement when you have a “therapy” and there’s no one to interact with? Not much, if the pharmaceutical imaginary has been transduced by the social/relational quality of psychotropic medications evident in the data we obtained.

Given the inherently social nature of humans, it is anthropologically unsurprising, then, that people anthropomorphize their medications and develop a social and psychological relationship with “it” or “them.” This relationship is intricately complicated by the unknowable and mysterious conjunction of the self, the illness, and the medication (see figure 1 above). What is the “it”? Medication? Disease? Myself? How as a matter of experience can these three (four, if we include God) be separable? How, as an entangled process of the self, do “we” all get along? Is this self-process cooperative or embattled, foreign or familiar, fixed or in flux? The narratives of research participants show that the process of taking medication is one in which the proper social relations must be actively managed.

#### PARADOXES OF LIVED EXPERIENCE WITH PSYCHOTROPIC DRUGS

Ultimately, the management of proper social relations must take place in the context defined by several paradoxes of lived experience generated by psychopharmaceutical treatment that create significant ambivalence in the process of recovery from psychosis (table 4). Perhaps the most wrenching dimension of subjectivity in relation to taking antipsychotic medications is the despair and alienation created by the paradox of “recovery without cure.” When prescribed these medications in the United States, patients are nearly always told that they must take them for the rest of their lives to alleviate symptoms and avoid relapse (see Dumit 2012 for elucidation of pharmaceutical regimes as “drugs for life”). They are explicitly given the grim news that there can be no “cure”—only management—of their condition. We can hold in abeyance the questions of whether interminable treatment is empirically justified longitudinally given the right personal strategies and peer support, or

TABLE 4 PARADOXES OF LIVED EXPERIENCE FOR PERSONS TAKING ATYPICAL ANTI-PSYCHOTICS

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- Recovery *without* cure
  - Stigma *despite* recovery
  - “Crazy” or “fat”
  - Fault-free biochemical disease *yet* characterological “defect”
  - Sexless and genderless *yet* desire and gendered conflicts
  - Social developmental problems *yet* pharmaceutical “management” without psychotherapy
  - Felt need for medication *in face of* fears of addiction, toxicity, and chronicity
- 

how it contributes to sustained profit flow for pharmaceutical companies. Persons invariably process this clinical information with great ambivalence and conflict. One woman drew a picture of herself without eyes: “[I had] blinded myself to the fact that the medication could not ‘cure’ me.” In an example of poignant confusion about the possibility of cure, a Euro-American man said:

I’d like to be healthy, and I’d like my illness to be in remission. And I’d like to be cured of my illness if it’s possible, and, uh, if, to the best of my knowledge, is that there’s not a cure for schizophrenia. But, like I said, it depends on the doctor’s philosophy too. Some say there are cures for all illnesses, some say there aren’t. And some say you can put illnesses in remission, and cure them, so I don’t know.

The deep desire for cure is no different in Ghana, where the anthropologist Ursula Read finds that Ghanaians regularly seek “hospital medicine” for mental illness—often *before* going to the local shrine. The paradox of “recovery without cure” thus poses a problem for global mental health in low- and high-income countries alike. As Read (2012: 438) observed, “Campaigns to scale up mental health services in low-income countries emphasise the need to improve access to psychotropic medication as part of effective treatment yet there is little acknowledgement of the limitations of psychotropic drugs as perceived by those who use them” (2012: 438).

Among the people she worked with, Read finds that

whilst medication undeniably brings benefits for many with severe mental illness, such campaigns seem to have glossed over the limitations of psychotropic drugs, particularly antipsychotics, and the ambivalent attitudes they provoke in those who take them. In many cases antipsychotic treatment had been discontinued, even where it had been recognised to have beneficial

effects. The failure of antipsychotics to achieve a permanent cure also cast doubt on their efficacy. (438–39)

On the one hand, having been through terrible experiences of psychosis, the afflicted and their kin often wish to do nearly anything to avoid the recurrence of such an experience ever again. On the other hand, news that there is no cure and will be no cure cannot be unwaveringly accepted since the existential condition of humans afflicted with disease is to harbor hope that somehow, some way, the nightmare they have lived has simply got to come to an end. Bargaining for sanity and life, they have done their fair share by enduring hospitalizations and taking medications.

Another irreconcilable paradox is the forced choice between psychosis and side effects, or in the words of one participant, to be “crazy or fat.” This paradox is fraught by the perverse practices of pharmaceutical companies that shaped clinical practice prior to the remarkably overdue “black box” warnings that were at long last issued by the FDA (2003, 2005, 2008) for atypicals as well as earlier antipsychotics. For example, Janssen Pharmaceuticals ran deceptive ads for Risperadal published in the *American Journal of Psychiatry* (156.9 [1999]: A41–43), the main copyrighted message of which was, “Efficacy uncompromised by excessive weight gain.” This apparently purposefully unclear ad played on a double meaning of *uncompromised*. Did the ad mean that there was no excessive weight gain that might compromise efficacy in the form of psychotic symptom control or that there would be excessive weight gain but it would not compromise efficacy? Ultimately, like persons prescribed these medications, clinicians are encouraged to “choose fat, not crazy.” Government-mandated black box warnings finally let the “consumer” know that weight gain is substantial (in the SEACORA study, we estimated that this was not infrequently 40 to 80 pounds) and constitutes not only a serious health problem in the form of obesity but also diminished social status through harsh societal stigma. The black box warnings also informed patients that atypical antipsychotics could lead to premature mortality (“increased risk of death compared to placebo”) when used by elderly dementia patients. The warnings also finally acknowledge the extensive and serious metabolic syndrome problems of hyperglycemia, diabetes mellitus (for which elevated risk occurs also in earlier antipsychotics such as haloperidol and thioridazine), along with cerebrovascular adverse events (stroke, death).

A paradox of lived experience can also be traced to the familiar but unwelcome dehumanization of persons with schizophrenia that leads to

the broad cultural assumption and not infrequently the clinical advice that they should not date or be active sexually—and certainly not reproduce. This was deeply troubling to participants and a matter of shame. Many have, or would like to have, active sexual or romantic relationships and resent the subtle insinuation across a variety of social settings they encounter that, unlike their healthy counterparts, they should not be involved in romantic entanglements, parental duties, or gendered identities.<sup>26</sup>

Meanwhile, patients are recognized to have social and developmental problems but are expected to rely primarily on pharmaceutical treatment, with little psychotherapeutic support. While accepting the need for medication, they fear they may be poisoned or become addicted. Though the disease model that has generated the root metaphor of the disease as a biochemical imbalance absolves patients from guilt, a lingering sense that the disease is also associated with some kind of character defect haunts them. The specter of stigma remains ever present both as a social fact and as a lived experience and is rendered paradoxical insofar as stigma persists despite recovery.

Another kind of paradox embedded in the ideology of contemporary biological psychiatry itself is the simultaneous denial of the relevance of the will and preoccupation with whether it is present, absent, or in a process of degeneration. In an analysis of Kraepelin's conception of dementia praecox as a pathology of the will, Byron J. Good (2010b) has underscored this problem by observing that "the absence of a robust conception of the will or volition in psychiatric nosology and theorizing" has created a "conceptual vacuum" in the realm of the voluntary (173). This is of considerable significance given the pervasive problem faced by participants that they will become the objects of social stigma despite their subjectively experienced improvement. Nearly all (96 percent) reported their experience of stigma daily across a variety of social settings such that, like the disease of schizophrenia itself, stigma is a potent force against which they must struggle vigorously. This is true even though many participants appear to endorse the notion that they have a biochemical imbalance that is theoretically "fault-free"; they still worried that having such an "imbalance" rendered them deficient or flawed, in effect generating a form of self-stigmatization. Against this obstacle, recognizing that the subjective experience of recovery is not limited in scope to symptom alleviation or medication compliance creates a space for agency and will in recovery from schizophrenia. Individuals actively participate in the work of recovery (Deegan 2005). The dimension of

personal agency also extends the process of recovery away from the ill individual and into complex relationships with others. These social relations tend to deemphasize illness, highlighting the fact that their problems, success, sadness, and joy are not bounded by the illness but are instead informed by normatively imagined cultural orientations. Yet, as Myers (2010, 2015) demonstrates, the recent emphasis on recovery not only as possibility but also as neoliberal requirement places heightened and potentially stressful expectations on patients. This completes the vicious circle back to recovery without cure.

## CONCLUSION

Across many locales and for many decades, the familiar biomedical narrative of psychotropic drugs as chemical compounds with biological effects has become a matter of cultural common sense. Availability and use of psychopharmaceuticals can hardly be taken for granted, though, since global socioeconomic inequity can limit or preclude access. Indeed, discriminatory policies on mental health care have often created unequal and in some cases grossly inadequate access even to relatively inexpensive WHO-dubbed “essential medicines,” let alone the “gold standard” of available treatments for serious mental illness. This is often the case even in high-income countries, where fewer than half of persons with serious mental illness actually receive any treatment at all,<sup>27</sup> but it is worse still in middle- and low-income countries where nearly three quarters of the affected population go without care (WHO 2013: 8).<sup>28</sup> Thus while psychiatrists in Indonesia, for example, are keenly aware of the most recent psychopharmacological compounds through pharmaceutical company-sponsored conferences, such knowledge is functionally irrelevant in light of the prohibitive cost involved (B. Good 2010a). So while the cultural presumption of efficacious biochemical effects is widespread, so too is the expectation of inevitable (if lamentable) “scarcity” of their distribution. Farmer and colleagues (2013) have critiqued the validity of the presumption and acceptance of “scarcity” regarding urgent health care. Anthropological studies of the global circulation of biomedicine and psychopharmacology have made significant advances in understanding social structural and market forces (Lakoff 2005; Petryna, Lakoff, and Kleinman 2007; Dumit 2012), as well as with respect to cultural influences on seeking, prescribing, taking, and responding to psychotropic drugs (Jenkins and Carpenter-Song 2005; Carpenter-Song 2009a, 2009b; Floersch et al. 2009).

In the United States, intensifying economic inequality can render any kind of treatment out of reach since large proportions of the population can neither fill a prescription nor see a doctor. Indeed, the United States exists as an “outlier” among industrialized countries with competitive health insurance markets (How et al. 2011). Considering health overall, there is a pervasive pattern of shorter lives and poorer health over the course of the life span compared to other high-income countries (Institute of Medicine 2013). Access to government-provided coverage of treatment for persistent mental illness is contingent on having income at the poverty level, a situation that encourages a kind of structural poverty among those who avoid obtaining employment to remain eligible to obtain medication. Yet structural economic conditions have not diminished awareness or efforts to seek out drugs that family and individuals think might be useful (Duncan 2012, 2015; B. Good 2010a; M. Good 2007; Basu 2014; Ecks 2013). Pharmaceutical companies, health care organizations, governmental agencies, media, schools, and family advocacy groups circulate discourse on psychotropic drugs as potent biological agents globally.

Lively controversy over the benefits and hazards of psychopharmacology occupies a prominent place in contemporary discourse on mental health. Proponents of psychotropics and critics whose judgments are grim hold their positions with equal fervor. In this chapter, I have drawn on ethnographic research to argue that any advance in this debate is contingent on close attention to the complexities of daily experience and the often substantial suffering among those who regularly take these medications. To be precise, experience-near perspectives must inform critical analyses of the economic and political dimensions of psychotropic use in order to demonstrate the numerous quandaries involved in understanding the remarkably indeterminate cultural, social, and biological effects of psychotropic drugs (Jenkins 2010a). The complexity of these effects is particularly marked in situations of serious and persistent mental illness treated with the most powerful of these agents.

The study of medication experience must recognize not only main effects and side effects but also a great many other “effects” that alter subjective experience in myriad ways and entail sacrifices in the context of self-presentation and social interaction across a variety of settings. Effects of the medication, in this sense, must be understood more broadly to include the influence of medications on one’s way of interacting with and inhabiting the world. For research participants as well as

others afflicted with mental illness around the globe, medications alone simply cannot be expected to produce a cure. One part of a solution would be to address the shortage of psychotherapy for such persons created by restrictive managed care and insurance coverage, along with addressing the long-standing but inadequate clinical perspective that psychotherapy is in any event of highly limited value for this population. Patients are grateful for their treatment, though it comes at the cost of facing multiple paradoxes of lived experience. They have the right to ask for more.