Meet Me Where I Am:
An Internal and External Assessment of Mental Disorder and Psychotropic Drug Treatment

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Introduction

I have so many thoughts. Thoughts, thoughts, ideas. Yes, of course, I’ll help you with that project. Oh, sure, that one, too. Wow, is that a snake bite kit? I need that. In fact, I need 10. Am I the only one who realizes the danger of- Ugh, can he please get out of my way? ---

I want to die. The sunset is bleeding. I’m bleeding. What happened yesterday? I can’t remember. The plants are decaying, and everything is black. Black and hopeless. Like my future. How can I ever get out of bed? What reason is there to continue? ----

Oh my god, what has happened? Who was that person? Who am I? What did I do? Who knows what? Will this happen again? ---

Irritability, impulsivity, racing thoughts, and hyperactivity, yet also hopelessness, anhedonia, apathy, and sadness. Drastic mood swings. These are some of the symptoms and experiences of a person with manic-depressive disorder, just one of many mental illnesses. Society, science, and medicine all too often tell these people that their mental illness means they are automatically impaired, disabled, and less than. Medicine also tells these individuals that the little blue pill in the orange-tinted bottle will fix them. And, sometimes, it will. That pill will bring much needed normalcy and refreshed ability to have a fulfilling and productive life. That pill will be tremendously helpful in treating that individual’s mental illness. But other times, it will not. And when that pill doesn’t work, medicine often tells these individuals that the next one will. And the next one after that. However, what medicine often does not tell these individuals is what is most important: that their mental illness is far more complex than that little blue pill, and that that little blue pill is far more complex than a simple solution.

Although these pills, or psychotropic drugs, have been shown to be tremendously helpful in treating mental illness, psychotropic drugs have also been shown to cause serious and harmful side effects, especially when prescribed inappropriately. Certain populations—such as the elderly, those with dementia and/or psychosis, and children—are especially vulnerable to these harmful side effects. Health agencies around the world have issued warnings about the risks of prescribing such medications to frail individuals, and current guidelines recommend their use only in cases where the benefits clearly outweigh the risks. Despite these warnings, an estimated 20%+ of all adults in the United States, and an estimated 87% of older adults with dementia in acute care geriatric units, are taking at least one psychotropic medication. Needless to say, the provision of safe psychotropic drug therapy is one of the greatest challenges in healthcare today; it is important for practitioners to thoroughly consider benefits and risks before administering these medications and to thoroughly assess efficacy after their administration.

To address these concerns, mental illness and the use and implications of psychotropic drugs are investigated here through the lens of a sample of patients at Terence Cardinal Cooke Health Care Center (TCC), a 559-bed skilled nursing facility with specialized units for geriatrics, HIV/AIDS, Huntington’s disease, Alzheimer’s disease and dementia, profound developmental
disability, and sub acute rehabilitation. The topics of definition, cause, diagnosis, treatment, stigma, corruption, and solutions are all investigated. Data on psychotropic drug use and its incidence with mental disorders at TCC were gathered and analyzed via retrospective chart reviews. Assessments of drug treatment efficacy from the perspective of the medical practitioner and the patient were recorded via interview and presented in the text and in mini case reports.

As the amount of diagnoses, prescription slips, and negative side effects increase, the diagnosis and treatment of mental illness must fix its flaws. Without this, the 1 out of every 5 adults in the United States, and rising from there, are left helpless at medicine’s potentially reckless, harmful, and unethical hands.

**Cause**

The complexity of mental illness begins at its core: the understanding of its root cause, a topic that is still heavily debated by scientists and clinicians alike. Historically, the cause of mental illness has been attributed to a wide and often fantastical variety of sources, such as spirits, the devil, or poor personal choices. More recently, as our understanding of the mind, brain, and body have matured, so have our hypotheses of the cause of mental illness; some believe mental illness is caused by a conflict between parts of the ‘unconscious,’ others by maladaptive learned behavior, by maladaptive thoughts, or by maladaptive social factors (neglect; abuse; trauma; toxic peer relationships; poor parenting; etc.), and still others by solely biological factors. Further, the theoretical orientation a person holds varies greatly not only among professionals, but also among common members of society. In his 2016 *UCSF News Center* article “The Key to Effectively Treating Mental Illness: Eliminate the Stigma,” managing editor Mike Billings explores this question of mental illness’ cause, among other things, with the help of medical doctors, researchers, and patients. Billings offers a perspective that many professionals, though not all, now generally agree upon: that mental health and disorder are the result of “a combination of nature and nurture,” a perspective that integrates many of these aforementioned theories (Billings, 2016). One of the key figures in Billings’ article, Dr. Stephen Hinshaw, vice chair for Psychology in UCSF’s Department of Psychiatry, expands upon this:

...One of the biggest changes [now] is the push to approach ... mental illness as a biological condition, interacting with contextual factors, instead of merely a social issue. ...

... Hinshaw points out that the default in society is that mental health is still under a person's complete control. However, research is revealing that the causes, like with cancer, are primarily biological. The understanding of the biological and genetic causes of mental illnesses still is developing as more research is done to understand the brain. (as cited in Billings, 2016)

Hinshaw’s statements inform several key points about the cause of mental illness.
The first is that the cause of mental illness has been shown more and more to be “primarily biological;” mental illness is not something that is “just in our head,” as some say, but instead a physiological difference in one’s brain. This is important for ethical reasons especially; the fact that mental illness is something that is legitimately out of a person’s control greatly influences the mental illness stigma, or how society views people with mental illness.

Hinshaw also acknowledges that, while the causes are likely primarily biological, there are other factors that affect the development of mental illness (“contextual factors”); as previously mentioned, Hinshaw offers a view that integrates nature and nurture. Ironically, this is important for the almost the opposite of the reason named above—this implies that, if nurture (i.e. environment) can influence the onset of mental illness, then nurture (i.e. environment) can also influence the “offset” or treatment of mental illness. This idea has been supported by research both at the basic science and clinical level; it is relatively well-known now that our brain is quite plastic and can be modified at the biological level as a result of environmental influence. However, to speak to the aforementioned stigma and question of mental illness being within one’s control, this plasticity and potential for influence by environmental factors is not unlike other illnesses, such as cancer, obesity, or heart disease; likewise, the treatment of a person with a mental disorder should be no different than that of a person with any of these.

Perhaps most importantly, Hinshaw carefully points out that, although research is revealing the cause of mental illness to be primarily biological, our “understanding… still is developing;” the mind and brain are home to the most unknown, mysterious parts of existence…and that can be scary. Yet, when talking about mental health, we cannot allow that fear to get in the way of how we understand and treat mental illness. Instead, we must recognize and account for that uncertainty in our treatment of these disorders.

While there is much more that could be said on the topic of cause, let us leave it at this: together, experience and research suggests that mental illness is (1) primarily caused by biological factors, with (2) social and environmental influence, but ultimately (3) we do not yet completely understand the biology or cause in general. These three key points regarding the cause of mental illness explain precisely why the concerns at hand surrounding mental illness—particularly regarding diagnosis, treatment, and stigma—exist and are important.

Flawed Approach

Despite their largely undetermined causes, mental illnesses are still recognized as medical disorders, leaving their consequences to be decided almost solely by scientists, doctors, and policy makers. In a lot of ways, this is a good thing. Historically, mental illness has been treated with unimaginable abuse and maltreatment, and with little oversight at all. Fortunately, we have since come a long way from the now-well-known horror that once took place at large psychiatric hospitals. With better understanding of mental illness has come better care for those who have one. However, in some ways, this development and modernization of our psychiatric healthcare
system has pushed past its limit; psychiatrists are now being forced to identify a problem and solve it before the problem itself is completely understood—which itself causes problems. Psychiatrists are pressured to set aside and ignore the reality that the causes of most mental illnesses are still unclear. They avoid discussing the problems that this reality causes, instead trying to apply the typical “diagnose and treat” model of medicine to mental illness in a premature way.

What we are left with today are the consequences of these two extremes, neither of which provides an accurate, realistic, or humane approach to mental healthcare. While we will hopefully, one day, reach a point where we do completely understand mental illness, and thus know how to diagnose and treat it, that day is not today. We need to recognize, not disregard, exactly where we are, and develop plans accordingly. The failure to do this—to create a mental healthcare model that fully addresses today’s developing state of our understanding of mental illness—is what causes many of the concerns at hand. Let’s explore these concerns, beginning with the issue of diagnosis.

**Diagnosis**

Two primary psychiatric diagnosis and classification systems exist: the Diagnostic and Statistical Manual of Mental Disorders (DSM) and the International Classification of Diseases (ICD). The DSM, published by the American Psychiatric Association, serves as the standard in the United States and is currently on its fifth edition (DSM-V). The ICD, published by the World Health Organization, is more common internationally and is currently on its tenth edition (ICD-10). The two have similarities and differences; however, those will not be discussed here. Instead, both systems will be discussed relatively interchangeably, with the DSM receiving slightly more attention, due to its greater influence on mental health and psychiatry in the United States. Notably, the electronic medical records at TCC classify disorders according to the ICD, as seen in Figures 1-3. In any case, both of these psychiatric classification systems include diagnostic criteria that classify symptoms based on pervasiveness, duration, resultant impairment, and age of onset, among other things. Generally, these systems require an individual to exhibit a certain number of all the possible symptoms of a mental disorder to qualify for a diagnosis.

Before delving into the intricacies of diagnosis, I want to briefly frame our discussion in the context of TCC. Last summer, Tess Cersonsky, a 2015 TCC intern, examined mental health at TCC in her report “Psychology and Psychiatry in Long-Term Care: Objective and Subjective Experiences in the treatment of mental disorders at Terence Cardinal Cooke Health Care Center” (Cersonsky, 2015). Data presented here from 2016 has been displayed alongside her 2015 data for comparison and reflection (Fig. 1-3). All mental disorders have been categorized into groups of disorders, as created by Cersonsky (2015; Appendix 1). It should be noted that a switch from the use of ICD-9 to ICD-10 at TCC appears to have taken place between 2015 and 2016. This
means all diagnostic codes used by Cersonsky to form her categories had to be translated into their ICD-10 code equivalents. This translation was not always exact, which may have slightly affected the data. Overall, 71% of the total TCC population in 2016 was diagnosed with a mental disorder, a slight increase from the 67% in 2015 (Fig. 1). As shown in the by-unit comparison, the HIV/AIDS (75%), Skilled Nursing (81%), and Huntington’s Disease (89%) units had the highest prevalences of mental disorders (Fig. 2). Over half of those individuals who were diagnosed with a mental disorder were diagnosed with three or more mental disorders (Fig. 3). These data clearly suggest that the need for this discussion at hand, regarding mental illness and its treatment, is well-founded, as it affects an enormous number of people.

Surprisingly, the high prevalence of mental disorder diagnoses at TCC and nationally does not mean that the foundation upon which these diagnoses are given is perfect. In fact, because the cause of many mental illnesses remains unclear, a gap exists in the foundation upon which diagnosis criteria can be decided, leaving ample room for flaw. As mentioned above, our current psychiatric diagnostic systems require an individual to present a certain number of possible symptoms of a disorder to qualify for the diagnosis. While intentions are good, these criteria are still far from perfect. In their American Medical Association (AMA) Journal of Ethics article “Diagnostic Brain Imaging in Psychiatry: Current Uses and Future Prospects,” Drs. Martha J. Farah, a cognitive neuroscientist at the University of Pennsylvania’s Center for Neuroscience & Society, and Seth J. Gillihan, a licensed psychologist and a Clinical Assistant Professor of Psychology at the University of Pennsylvania, discuss some of these flaws:

As an illustration of how far from being necessarily valid our current diagnostic categories are, consider the criteria for one of the more common serious psychiatric conditions, major depressive disorder. According to the DSM-IV-TR, patients must report either depressed mood or anhedonia and at least four of eight additional symptoms. It is therefore possible for two patients who do not share a single symptom to both receive a diagnosis of major depressive disorder. There are also commonalities of symptoms between categories. For example, impulsivity, emotional lability, and difficulty with concentration each occurs in more than one disorder. To the extent that our psychiatric categories do not correspond to “natural kinds,” we should probably not expect correspondence with brain physiology as revealed by imaging. Taken together, the fact that (a) different exemplars of a category can share no symptoms and (b) exemplars of two different categories may share common symptoms raises questions about the validity of the current diagnostic categories. (Farah and Gillihan, 2012)

Farah and Gillihan point out just two of many reasons to question the validity of our current diagnostic categories. Importantly, though, they demonstrate that our diagnostic systems attempt to pinpoint and define mental disorders when we know that we will fail at doing so accurately. To be clear, this is not a failure of the diagnostic systems; it is instead an inevitable flaw, a consequence of the reality that we do not yet understand the physiology well enough to precisely distinguish between diagnoses and identify pathologies. In fact, the attempt that these diagnostic
systems (and the people who decide on them) are making at identifying, distinguishing between, and categorizing mental illnesses is generally not a bad thing; doing this provides nomenclature and structure, facilitates research, and is a necessity for us to best help those with mental illness. Nevertheless, the diagnostic criteria and categories are flawed. The tension surrounding this comes when these diagnoses are applied and used without also active and consistent acknowledgement of their inevitable inaccuracy.

We must challenge ourselves constantly: what is the quality of these criteria, these assessments, and their ability to adequately distinguish between ‘normal’ and ‘abnormal’? The professor of Columbia University’s Abnormal Behavior course, a clinical psychologist herself, clarified, "Clinical psychologists don't use the words 'normal' and 'abnormal'. We use the terms, ‘Does the person meet criteria for a specific diagnosis?’” Her statement begins to demonstrate a concerning problem surrounding mental disorder diagnosis: the DSM’s use of a set of hard criteria, which a patient either meets or doesn’t meet, rather than a continuum from normal to pathological—a categorical, rather than dimensional, system. This begs an important question: does reality reflect what the diagnostic criteria assume, that a discrete line divides normal from dysfunctional? For many disorders and specialities of medicine, the answer is no. There is a spectrum from normal to dysfunctional. Consider blood pressure, for example: there is a spectrum that ranges from low blood pressure (hypotension) to normal to high blood pressure (hypertension), all with various added levels of severity. A similar picture can be painted with weight: underweight to normal to overweight to obese, again with added levels of severity.

Psychiatry is likely no different from these, despite what the DSM may imply. There is no line, but instead a continuum. There are people who are reserved, timid, shy, humble, and others who are confident, assertive, outgoing, and both types of people may be considered ‘normal.’ And then there are also extremes, encapsulated in part in diagnoses such as social anxiety disorder or narcissistic personality disorder. While this is an imperfect analogy, it is nevertheless likely the case that mental health and behavior, and thus many mental illnesses, are similar to blood pressure and weight, on a continuum of severity in which a clear distinction between ‘normal’ and ‘abnormal’ is not possible. Imagine the following scenario:

A certain mental illness, say narcissistic personality disorder, is in part caused by the overexpression of a protein in the neurons of a certain area of the brain, due to a mutation in a 10-nucleotide string of DNA. In one individual’s brain, the mutation is only in 2 nucleotides. The protein is overexpressed, but moderately so. This individual shows a slightly grandiose sense of self-importance (one of the 9 criteria), among other symptoms. In a second individual’s brain, the mutation is in all 10 nucleotides. The protein is severely overexpressed. Likewise, this individual’s grandiose sense of self-importance is much more severe.

It is not unimaginable that such a scenario, or something similar, is an accurate portrayal of the underlying biology of mental illness, and we just have not yet figured it out. If this were true, in today’s context, the psychiatrist would have no insight into that biology; no tests for ‘number of
mutations’ yet exist. All the psychiatrist would see is the behavioral difference in the severity of each person’s “grandiose sense of self-importance.” In this scenario, the “grandiose sense of self-importance” criteria could be checked off in both cases, even though each individual’s presentation is very different. Important information about each patient is lost. In this way, the DSM’s categorical approach to classifying symptoms (i.e. “indicated by the presence of at least 5 of the following 9 criteria”) does not accommodate the likely reality that the difference between ‘normal’ and ‘abnormal’ occurs on a spectrum that relates symptom intensity to problem-causing ability.

**Physician Subjectivity and Interrater Reliability**

As has been implied, the assessment of these criteria can also be quite subjective. For the great majority of mental illnesses, assessments lack laboratory-based diagnostics; because we do not know the pathophysiology of the majority of these mental illnesses, we cannot test for such with a quick blood test or x-ray. Most diagnoses are left to evaluation by a clinician. This leads to variability and thus calls into question diagnosis reliability for at least three reasons: (1) humans are inevitably subjective, (2) the mental-health-related expertise of the diagnosing clinician can vary considerably, and (3) for a single mental disorder, several methods for assessment often exist, and these methods are often not used in tandem, despite the fact that they should be.

Such diagnosis objectivity has been shown to vary between disorders and treatment settings. As a measure of diagnosis objectivity, several studies examine ‘interrater reliability,’ or the degree of agreement among raters or, here, clinicians. Some psychiatric diagnoses, such as major depression and bipolar disorder, have been shown to have interrater reliabilities that are generally on a par with those in other medical specialties (Pies, 2007). However, several others, such as schizoaffective disorder, schizophrenia, and ADHD, have been shown to have much worse interrater reliability (Maj et al., 2000; Folsom et al., 2006). Further, interrater reliability was shown to vary greatly depending on setting. According to Folsom et al. (2006), “for both schizophrenia and major depression, variability was significantly higher in jail and the emergency psychiatric unit than in inpatient or outpatient settings.” The former are both places where there are limited visits between patient and clinician. This suggests that, to decrease the subjectivity of diagnoses, there is a need for doctors to see patients more often. However, as will later be discussed, this need is not always met, even at TCC. Nevertheless, in all areas of medicine, psychiatry especially, an unavoidable amount of clinician subjectivity exists. This subjectivity is important to not dismiss, as it adds yet another source of flaw that can negatively affect the quality of patient treatment.
Mis- and Over-Diagnosis

This variability and subjectivity can lead to misdiagnosis and overdiagnosis, which is clearly problematic. Tess Cersonsky touched on this in her discussion of the Episodic Mood Disorder (EMD) diagnosis, which she described as seeming to be “a ‘catch-all’ category that makes up any unspecified mood disorder that does not fall into any of the other categories” (Cersonsky, 2015). In 2015, when Cersonsky wrote her paper, 55% of the HIV/AIDS residents at TCC were diagnosed with EMD. Now, in 2016, 32% are diagnosed with the equivalent (Fig. 2).

Reflecting on the large number of people who have this vague diagnosis, Cersonsky questioned:

… when someone has anger or frustration related to their condition or placement in a nursing facility, episodes of mood disturbance are so incredibly understandable. Residents are told what to eat, when to eat, when they get to shower, when they can go outside – anyone who experienced a life outside these walls has reason to act out or to experience distress. If you have a background of difficulty or a chronic, deadly diagnosis, if you have some anger at your life or the people who constrict you to there – choosing how you respond to a situation is something you can control, and an outlet of frustration. But is it to be classified as “Episodic Mood Disorder”? (Cersonsky, 2015)

Cersonsky humanizes well this problem. While it is not certain whether the specific instances to which Cersonsky refers are examples of true overdiagnosis, overdiagnosis is known to be a problem, and the concerns that Cersonsky raises are extremely valid. It is important that doctors are not using mental illness as an explanation for behavior that may actually be quite ‘normal’ behavior, given the circumstances. Yet, this can and does indeed happen. Psychologists, psychiatrists, and other physicians sometimes “emphasize a narrow, medically-oriented ‘symptom picture’ that is devoid of the psychosocial context in which the so-called symptoms emerge” (Levine, 1997, p. 196). How many of us can say with confidence that we would not react to the circumstances described above in the same way? And if we cannot, does that mean we are all mentally ill?

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Together, all of these concerns call into question the true meaning of diagnosis. Many would agree that a diagnosis is the identification of an illness or disorder, of an abnormality. However, still, a grey area remains; no consensus definition of abnormality or disorder exists.

Normal versus Abnormal

These definitions of normal and abnormal involve deep and difficult—but incredibly important—ethical questions. When do personality traits change from just different to bad? When do they become symptoms? Is it when they cause the individual to suffer? Is it when they
cause society to suffer? Are these symptoms always bad? Is that distinction between normal and abnormal static, the same for every person, or dynamic? Does ‘abnormality’ reflect a dysfunction of the individual, or is this a failure of the environment to accommodate human diversity? Could it be both? These are the questions that are so incredibly important for not only every psychiatrist, psychologist, and clinician to ask daily, but also for all members of society to consider. Many of these questions are represented in a list of indicators of abnormality, which are outlined in one of the field’s leading textbooks, *Abnormal Psychology* (Hooley et al., 2016), where this list of indicators is also accompanied by a warning that even it was not compiled with consensus and thus remain questionable. These indicators include:

1. Subjective distress (e.g. “I’m not myself”)
2. Maladaptiveness (e.g. evolutionarily disadvantageous)
3. Statistical deviancy (e.g. there is a statistical norm and steps away from the norm)
4. Violation of standards of society (e.g. assume that a mentally healthy person adheres to the standards of society)
5. Social discomfort (e.g. we feel a discrepancy between us and them)
6. Irrationality and unpredictability (e.g. are they engaged in rational or irrational thoughts)
7. Dangerousness (e.g. danger to others and to self)

Represented in this list, there is, on one hand, the scientific, biological side, where mental illness is defined as a physiological disruption. This scientific side probably agrees most with the “maladaptiveness” and “statistical deviancy” indicators above. But, with brains that are all so very different, it is very difficult to truly define the norm and pinpoint when something becomes abnormal, especially if there is a spectrum. For this reason, science is not enough; we must also look to philosophy and ethics for answers. That is when things become more complex. We must ask: is it *right* to deem someone mentally ill just because they “violate societal standards”? Is it *right* to deem someone mentally ill because they make you “uncomfortable”? Clearly, these indicators must not be accepted mindlessly, without reflection.

**Stigma**

While many of the indicators above raise alarming questions, one stands out, in particular: social discomfort. These two words allude exactly to perhaps the biggest and most important problem surrounding mental illness: the stigma. Society has deemed people with mental illness as bad, dangerous, dirty, unlovable, people who don’t belong, people from whom we should keep our distance, people we should fear. In her book *Voices of Hope for Mental Illness: Not Against, With*, as referenced in the *NPR Invisibilia* special entitled “The Problem with the Solution” (Miller & Spiegel, 2016), Jackie Goldstein, former professor of Psychology at Samford University, argues that:
Too often community members only "experience" mental illness through dramatic or dire media stories that fail to inform us about the real world of mental illness. Thus, stigma feeds, and is fed by, myths and misunderstandings leading to a community sense of hopelessness and fear of mental illness. (Goldstein, 2016)

This stigma is recognized, too, by Dr. Hinshaw, among dozens of others: “People want to keep their distance from people with mental illness more than any other group in society” (as cited in Billings, 2016). This stigma stems, in part, from gross misunderstanding and results in vast and deeply harmful consequences.

On one hand, this stigma, and the underlying misunderstanding, can lead people to not truly recognize mental illness when it is present, inciting sentiments such as ‘they are just in a phase,’ ‘they’ll get over it,’ and ‘they’ll snap out of it.’ Statements like these serve as evidence that many people do not realize that mental illness is like other illnesses, rooted in biology, and in this way, should be medically treated and socially viewed as such. How a person behaves or emotes is not just the result of them choosing to “misbehave” or “act out;” instead, it often develops, at least in part, due to a difference in their physical makeup, something completely out of their control, much in the same way that a gene that predisposes you be taller or heavier interacts with environmental factors, such as the food you eat and activities in which you participate, to produce a final result. Yet, many still do not view mental illness in this way. This suggests a great need for society to truly understand the cause of mental illness—that mental illness truly is a physical, biological illness—and that, like other physical biological illnesses, mental illness can be treated.

More than that misunderstanding, and ironically almost in contrast to that misunderstanding, this stigma can lead to the exact opposite: premature labeling of different, “difficult” people as mentally ill when they may not be; the use of mental illness as a weapon to label normal human variability as abnormal and wrong. This echoes the discussion above about mis- and over-diagnosis, with the example of Episodic Mood Disorder. It seems that clinicians and society in general tend to overpathologize human variability. In this way, mental illness can be used as a crutch used to resolve society’s failure to recognize that normal is a broad spectrum. People use mental illness as a label for people who are different, a way of saying, “your differences are invalid and need to be normalized.” Importantly, this consequence reflects the fact that mental illness itself is seen as a reflection of the quality of that person and becomes the identity of that person. For many, this stigma results in mental illness becoming synonymous with saying that a person is dirty and faulty.

In either case, society’s actions are rooted in non-acceptance and a corrupt definition of abnormality. Society is not defining mental illness and abnormality as something that is causing “subjective distress” or something that is “maladaptive” or “dangerous;” instead, society is defining mental illness predominantly as something that causes “social discomfort.” Mental illness is viewed not as a physiological disruption that is inhibiting the person who has the mental illness from living a fulfilled life, but instead as a flaw in that person’s identity. Mental
illness is viewed first in terms of the burden it causes society, and only second in terms of the challenge it causes the patient. Too often, our view of mental illness is devoid of compassion, and replaced with fear and judgement. This means that, while society and medicine should be treating and diagnosing individuals with mental illness out of the intention to help them improve their lives, we are often completely failing to do so.

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These questions of diagnosis issues, the definition of mental illness and abnormality, and the stigma surrounding mental illness raise serious ethical questions, especially when put in context of the consequential treatment options.

Treatment

Introduction and History

In fact, the matter of treatment is arguably where the greatest amount of controversy lies. There is little disagreement that the most common treatment for mental illness is pharmacotherapy, or medication (National Institute of Mental Health, 2008). In general, the medications that are prescribed to those with mental illness are known as psychotropic drugs, or chemical substances that change brain function and alter mood and behavior. Psychotropic drugs generally fall into a few large categories. These include: (1) antidepressants, (2) anxiolytics (antianxiety drugs), (3) mood stabilizers (antimanic drugs), (4) antipsychotics, (5) stimulants, (6) sedatives/hypnotics, and (7) others. At TCC, 58% of the total population is prescribed at least one psychotropic medication (Fig. 4), with patients on the Huntington’s Disease unit being prescribed significantly more psychotropics than any other unit (Fig. 5). Over half of the individuals who are prescribed psychotropics are prescribed more than one psychotropic, which raises a high concern of adverse drug interactions (Fig. 6). These numbers have remained effectively constant, at least for anxiolytics and antidepressants, or increased, for antipsychotics, since 2015 (Fig. 7).

Psychotropics drugs are relatively new developments, but have grown quickly in their prevalence since their inception. It was only a little over 50 years ago, in the 1950s, when psychiatry’s first “wonder” drug, Thorazine, was introduced to the market. Since then, dozens of new psychotropic drugs have been and continue to be developed and introduced. With their development has also come their quick rise as the primary mode of treatment for mental illness. Dr. Marcia Angell—physician, Senior Lecturer in the Department of Global Health and Social Medicine at Harvard Medical School, and former Editor-in-Chief of the New England Journal of Medicine—comments on this history and rise of psychotropics in the first part of her two-part

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1 These numbers do not include antimanic drugs or stimulants, and thus are probably low in their projections.
The *New York Review of Books* article, “The Epidemic of Mental Illness: Why?” Here, Angell recounts:

Nowadays treatment by medical doctors nearly always means psychoactive drugs, that is, drugs that affect the mental state. In fact, most psychiatrists treat only with drugs, and refer patients to psychologists or social workers if they believe psychotherapy is also warranted. The shift from “talk therapy” to drugs as the dominant mode of treatment coincides with the emergence over the past four decades of the theory that mental illness is caused primarily by chemical imbalances in the brain that can be corrected by specific drugs. That theory became broadly accepted, by the media and the public as well as by the medical profession, after Prozac came to market in 1987 and was intensively promoted as a corrective for a deficiency of serotonin in the brain. The number of people treated for depression tripled in the following ten years, and about 10 percent of Americans over age six now take antidepressants. The increased use of drugs to treat psychosis is even more dramatic. The new generation of antipsychotics, such as Risperdal, Zyprexa, and Seroquel, has replaced cholesterol-lowering agents as the top-selling class of drugs in the US. (Angell, 2011a)

It is clear that the use of psychotropic drugs exploded quickly, and their prevalence has still only continued to grow. According to a study conducted by Medco Health Solutions that analyzed trends in psychotropic drug use, “the number of Americans on medications used to treat psychological and behavioral disorders has substantially increased since 2001; more than one-in-five adults was on at least one of these medications in 2010, up 22 percent from ten years earlier” (Medco, 2011). At TCC, these numbers are even higher. More than half (58%) of all patients at TCC are prescribed at least one psychotropic drug (Fig. 4), and that is considering that 71% of TCC patients have a diagnosed mental illness (Fig. 1); this data suggests that the vast majority of patients with mental illnesses are treated with pharmacology at TCC, too.

Since their development, the use of psychotropic drugs has been debated; their biological foundation, ethics, safety, and efficacy have all been called into question, and on none of these questions is there a consensus answer. Given that so many people nationally and at TCC alone are being treated with psychotropics, and given the complexity of mental health that we have already discussed above, it is imperative that we look deeper into these drugs and their use.

**Biological Foundation**

Just as the cause of psychiatric disorders is still unclear, so are the effects of many psychotropics drugs; there is much that is still not understood about the way that many of these drugs modulate our brain, and the way that our brain modulates itself in response to these drugs. As perhaps alluded to above, most psychotropic drugs have been designed to primarily modulate the brain by altering the balance of neurotransmitters in some way. In the *New York Review of Books* article “‘The Illusions of Psychiatry’: An Exchange,” an article that responds to Dr.
Marcia Angell’s aforementioned article, Dr. John Oldham—former President of the American
Psychiatric Association—even admits that “although psychotropic medications have been found
to alter the balance of neurotransmitters in the brain, there is no consensus on whether these
imbalances are causes of mental disorders or symptoms of them” (Oldham et al., 2011). In fact,
more and more research is coming out that suggests that this traditional account of mental illness
as a result of chemical imbalances is simply wrong, or at the very least, far from the whole
picture. This means that our predominant treatment for thousands of patients is a set of drugs that
are known to be unspecific, imprecise, and potentially inaccurate in truly treating the
still-unknown causes of mental illness… an alarming conclusion.

Until we do truly know the causes of mental illness and likewise the effects of
psychotropics on treating them, we must consider all questions, possible consequences, and
potential realities. Dr. Angell posits one such possibility:

…it [is] entirely possible that drugs that [affect] neurotransmitter levels could relieve
symptoms even if neurotransmitters [have] nothing to do with the illness in the first place
(and even possible that they [relieve] symptoms through some other mode of action
entirely). As Carlat [a psychiatrist who wrote the book Unhinged] puts it, “By this same
logic one could argue that the cause of all pain conditions is a deficiency of opiates, since
narcotic pain medications activate opiate receptors in the brain. Or similarly, one could
argue that fevers are caused by too little aspirin. (Angell, 2011a)

Although this scenario cannot be confirmed nor denied at this point, we must consider its
possibility, especially given the growing research that suggests deep cracks in the ‘chemical
imbalance theory’ of mental illness. We must ask ourselves: if this scenario were proven true,
would psychotropics really be treating pathology, or just unnaturally altering the brain to provide
‘symptom relief’? If the answer is the latter, would their prescription still be ethical? Should this
unnatural alternation of one’s brain be the ‘norm’? Even these questions are difficult to answer
and must take into account many other factors, such as how these drugs affect the patient
physically, behaviorally, and mentally and whether there are alternatives, all of which are topics
that will soon be discussed.

Long-term effects and withdrawal.

To answer these questions, one must consider the long-term effects of these drugs and
whether they are harmful. Angell again considers one possible scenario:

If psychoactive drugs do cause harm, as Whitaker [Harvard University fellow, journalist,
and author of the books Anatomy of an Epidemic: Magic Bullets, Psychiatric Drugs, and
the Astonishing Rise of Mental Illness in America and Mad in America] contends, what is
the mechanism? The answer, he believes, lies in their effects on neurotransmitters. It is
well understood that psychoactive drugs disturb neurotransmitter function, even if that
was not the cause of the illness in the first place. Whitaker describes a chain of effects.
When, for example, an SSRI antidepressant like Celexa increases serotonin levels in synapses, it stimulates compensatory changes through a process called negative feedback. In response to the high levels of serotonin, the neurons that secrete it (presynaptic neurons) release less of it, and the postsynaptic neurons become desensitized to it. In effect, the brain is trying to nullify the drug’s effects. The same is true for drugs that block neurotransmitters, except in reverse. For example, most antipsychotic drugs block dopamine, but the presynaptic neurons compensate by releasing more of it, and the postsynaptic neurons take it up more avidly. (This explanation is necessarily oversimplified, since many psychoactive drugs affect more than one of the many neurotransmitters.) (Angell, 2011a)

Again, such a scenario cannot yet be proven or disproven with the knowledge we have, but nevertheless, such a scenario must be considered. That said, this scenario does, in effect, represent the commonly-accepted explanation for the cause of drug withdrawals. A significant body of research has shown that long-term use of psychotropic drugs does in fact result in “substantial and long-lasting alterations in neural function,” as stated by Dr. Steve Hyman, former director of the NIMH and former provost of Harvard University (as cited in Billings, 2016). If we know that, by prescribing a patient a psychotropic drug, we are substantially changing their neural function, and in effect, their most true identity, should we not be incredibly cautious and careful when doing so?

Uncertainty.

Realistically, the answer to so many of our questions is “we don’t know,” and since “we don’t know” means anything is possible, then anything is possible should mean, yes, doctors should be incredibly cautious and careful when prescribing psychotropic drugs. Dr. Abigail Zuger summarizes this tension in her 2016 New York Times article “Book Review: ‘Ordinarily Well: The Case for Antidepressants’”:

Doctors may someday be able to map every patient’s errant neurotransmitters and neural dead ends, then supply the precise chemical needed to restore normal traffic patterns. For now, though, prescribers are stuck with educated guesswork. (Zuger, 2016)

As Dr. Zuger suggests, the reality is this: much of psychiatry today is shots in the dark, with only a few interspersed sparks of light and clarity. For now, this reality is unavoidable. Our understanding of these drugs and, more so, the illnesses that they aim to treat is in constant flux as more research is conducted to understand the brain. While this uncertainty should not stop medical professionals from using these drugs to help patients, this uncertainty should impose on medical professionals a huge responsibility to account for this ignorance when prescribing these drugs.
Efficacy and Safety

Despite these important foundational uncertainties, the most practical questions regarding psychotropic drugs still remain: do these drugs work, and are they safe? Yet, unsurprisingly, the answer to these, too, is not black and white. The opinions of medical professionals and patients alike are incredibly split.

Benefits.

In many ways, the recent development of psychotropic drugs is a miracle, as they have helped give millions of individuals with serious mental illness restored hope. For example, Dr. Peter Kramer, a long-time psychiatrist, author of “Listening to Prozac,” and professor at Brown Medical School, adamantly defends antidepressants because of this reason. In her aforementioned article, Dr. Zuger summarizes well Dr. Kramer’s bottom line: “he argues that antidepressants work just about as well as any other pills commonly used for ailing people, and that the drugs keep people who take them reasonably healthy” (Zuger, 2016). It is undeniable that these drugs have been tremendously helpful to thousands of people with mental illnesses. I want to be clear in recognizing this, because this really is very important. When it comes down to it, as Dr. Oldham writes:

The bottom line is that these medications often relieve the patient’s suffering, and this is why doctors prescribe them. The difference is that today, thanks to medical and therapeutic advances, there is real help for those who suffer the devastating effects of mental illness. (Oldham et al., 2011)

For some, the benefits of psychotropics really do outweigh the potential harms. However, for others, the picture painted above unfortunately is not the reality they experience.

Burdens.

Psychotropic drugs are very much a double-edged sword, offering the potential for help, but also bringing a plethora of risks and harmful side effects. When asked how her decisions about psychotropic drugs are made, TCC’s psychiatrist, whose name I will withhold for confidentiality, explained some of these considerations, focusing mainly on the drugs’ effects on the rest of the body and other medical problems. She used Seroquel, an antipsychotic, as an example. Seroquel, she explained, can exacerbate symptoms of diabetes and high cholesterol, leading to potential weight gain, increased blood pressure, and increased blood sugar. A patient can actually develop diabetes as a secondary to the use of Seroquel. She gave a few other examples: Abilify often has less side effects in regard to the lipid and glucose profile; steroids may cause a patient to develop depression or psychosis; and most antipsychotics can cause
extrapyramidal symptoms, such as rigidity in arms and parkinsonism (i.e. abnormal gait and tremors). In addition to the considerations that she mentioned, these drugs have also been shown to affect sleep, appetite, and cardiovascular health. All of these side effects must be taken into account when prescribing a drug. One potential, and not uncommon, result is that doctors will prescribe psychotropics and then treat the secondary conditions with even more medications. Dr. Angell echoes these concerns and consequences, explaining that:

...SSRIs may cause episodes of mania, because of the excess of serotonin. Antipsychotics cause side effects that resemble Parkinson’s disease, because of the depletion of dopamine (which is also depleted in Parkinson’s disease). As side effects emerge, they are often treated by other drugs, and many patients end up on a cocktail of psychotropic drugs prescribed for a cocktail of diagnoses. The episodes of mania caused by antidepressants may lead to a new diagnosis of “bipolar disorder” and treatment with a “mood stabilizer,” such as Depokote (an anticonvulsant) plus one of the newer antipsychotic drugs. And so on. (Angell, 2011a)

The side effects of these drugs are vast and not uncommon. They can lead to a seemingly never-ending cycle of a problem that is solved with a new prescription that causes a new problem that is again solved with a new prescription, which then can lead to more side effects caused by drug interactions, and so on and so on. These concerns about harmful side effects are only heightened when psychotropic drugs are prescribed to the elderly, children, patients with dementia, patients with compromised capacity, or patients with compromised ability to communicate, all of which are particularly relevant for the patient populations at TCC.

In any case, these drugs can cause severe physical, behavioral, emotional, and cognitive side effects. Psychotropic drugs, at their core, are used to alter someone’s brain and, effectively, to change who a person is. When that goes awry, it has huge implications.

The harm caused by psychotropics can be seen, too, in the exceeding difficulty of withdrawing them. Dr. Angell discusses these effects:

When Celexa is withdrawn, serotonin levels fall precipitously because the presynaptic neurons are not releasing normal amounts and the postsynaptic neurons no longer have enough receptors for it. Similarly, when an antipsychotic is withdrawn, dopamine levels may skyrocket. The symptoms produced by withdrawing psychoactive drugs are often confused with relapses of the original disorder, which can lead psychiatrists to resume drug treatment, perhaps at higher doses. (Angell, 2011a)

The occurrence of withdrawal symptoms only further demonstrates that, at both a molecular and clinical level, these drugs are drastically altering a person’s brain and body in a multitude of ways. This brings us back to those most practical questions: do these drugs work, and are they safe? It should be clear by now that the answers are not simple.
Benefit-harm ratio.

Let us review what has been considered thus far: the biological effect of psychotropics is debated; it is unclear whether psychotropics truly treat mental illness’ pathology or just independently alleviate symptoms; the long-term effects of psychotropic use is unclear; psychotropics have been shown to substantially alter normal neural functioning; and clinically, psychotropics can be tremendously helpful, but also tremendously harmful. Together, these uncertainties and considerations should lead to one conclusion: psychotropic drugs must involve incredibly careful and difficult decisions in which every single one of these considerations is recognized and in which the benefits and harms are vigilantly examined and weighed. A doctor should be expected to ask, with a concerned and critical eye: Is it ethically right to prescribe this psychotropic medication? Is it ethically right to prescribe this second or third or fourth psychotropic, or is it ethically right to withdrawal the drug and try an alternative? This benefit-harm analysis and these questions must be answered with the best interest of the patient as the first priority, because, ultimately, the goal of medicine should be to help an individual have the most meaningful and worthwhile life.

Unfortunately, it appears that this ideal far too often does not match reality. Despite the fact that these drugs involve a tremendous amount of uncertainty and potential harm, psychotropic drugs are widely prescribed and highly regarded. Why? If there are so many uncertainties, so much disagreement and debate, so much harm surrounding psychotropics, then why are they so extremely prevalent? Why is almost 60% of TCC’s population on these drugs (Fig. 4)? Why are over half of those on psychotropics at TCC on more than one psychotropic (Fig. 6)? Why is psychopharmacology so dominantly the treatment of choice?

Why is the ideal not the reality?

The answers to these questions appear to boil down to these three reasons: (1) self-interest, (2) corruption, and (3) lack of resources.

(1) Self-Interest

Unfortunately, the cynical view of medicine is sometimes—not too often, but often enough—reality; sometimes, doctors and nurses make decisions strongly influenced by self-interest. Medication is a pretty quick and easy fix, and this can be capitalized on, against the best interest of the patient.

Case 1: LN

LN was a patient that, due to the timing of his transfers and readmissions, I only met once. However, still, he and his story stuck with me. LN is a 49-year-old male diagnosed with
bipolar disorder and paranoid schizophrenia, and has a history of cocaine abuse. He had been at TCC for several months prior to my arrival. LN was known to regularly call 911 and threaten suicide. Shortly before my arrival at TCC (early June 2016), LN was transferred out from TCC and admitted into the psychiatric ward at a nearby hospital for about three months. After several psychiatrists deemed him psychiatrically stable and well enough, LN was discharged back to TCC.

The announcement of his return caused a lot of commotion. During morning report on the day his return was announced, the room reacted with dread, saying that they could not take care of him. Nevertheless, he was readmitted. Within 4 hours of readmission to TCC, he called 911 repeatedly, saying that “there is death hanging in the air” and that he was going to kill himself if they left him here. He was also reported to have busted open the doors of unit, saying that he was leaving and expressing that he was tired of being institutionalized. He was sent out to the psychiatric hospital because of superficial cuts on his wrist. However, he was again discharged from the psychiatric hospital back to TCC. Clearly, the situation with LN was tricky and something needed to be done to help him feel comfortable at TCC.

After all of this occurred, at the next morning report meeting, the medical director opened a discussion for solutions for him. Many of the nurses and nurse managers expressed that they weren’t very hopeful that anything would change, and were very resistant to trying anything new. However, the medical director explained, with resolve: When Mr. LN was in the psychiatric hospital, his social worker saw LN always in activities, and when he wasn’t in activities, LN was talking at the nursing station. He was able to sit with himself and feel settled. And the key is: between his transfer from TCC and his transfer back, his medications weren’t changed that much. What did changed were his ‘alternative treatments.’ To this, someone responded, “Yeah, he just needs attention” and another, “Before he was transferred, he had tons of volunteers sitting with him.” Eventually, the conversation ended with a statement from the medical director: “I think we need to come up with an idea that is non-pharmacological”.

When one first learns about LN’s case, one may easily understand the frustration that the nurses and nurse managers feel, having to care for someone who is incessantly calling 911 and not being successful at changing that. There is no doubt that his case is difficult. However, it is tremendously difficult cases like this one that truly challenge the quality of a healthcare provider. I think LN’s case is the quintessential case for our discussion.

I should be clear to say that I am really not in a position to comment accurately on the specifics of LN’s case and its challenges, as I have not witnessed much of it at all first-hand. That said, I can at least offer my thoughts on what I have seen.

When I think and think about LN’s case, I cannot help but to realize that this is someone with severe mental illness, someone who desperately needs to be seen as a human, just like you and me, who needs love and care. It is true, he does need attention. But why is that said with such a derogatory tone? He is tremendously sick. Yes, just like someone with Ebola virus or who just had an open heart surgery, LN needs attention. There is nothing abnormal or wrong about
that. He, especially, needs attention because that “attention” itself is what can directly help treat his particular illness. That is the beauty of our brain; it is malleable and can change in response to our environment, to the attention we do or do not receive. While we don’t know exactly how, or how much, or why attention helps modify the brain and behavior, we know it does. So why are we so opposed to trying this, yet so inclined to trying drugs, about which so much also remains unclear?

LN’s case demonstrates perfectly how self-interest can play into the decision of whether or not to medicate. It is easy to look to medication as a tool to calm someone down. Sometimes, that is in the best interest of the patient. But in a case like this, where medication changes have already shown to be relatively ineffective, it appears that healthcare providers are looking to these medications to help not the patient, but themselves, to relieve themselves of having to “deal” with that ‘difficult’ patient. That’s a problem.

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Attitude is so important in a medical setting, more than anywhere else. Doctors and caregivers are in a position of authority when they are treating patients, and for this reason, should be and are held to the highest level of integrity and responsibility. In the words of Dr. Marya Pollack, a psychiatrist who visited and spoke with us, decisions about psychotropics should be made with the best interests of the patient in mind to reflect the lowest dose and least medications that keeps [the patient] functioning with the fewest secondary side effects; “less is more.” LN’s case so distinctly shows the importance of this attitude—of integrity and genuine care—in medicine, through both extremes. On one hand, so many of the psychologists, social workers, psychiatrists, doctors, nurses, and nurse managers had lost all willingness to try with Mr. LN. Yet, the Medical Director and some others showed the opposite of this. They were able to set aside the influence of self-interest and stand up for what is in the best interest of this patient: an alternative, non-pharmacological treatment.

(2) Corruption

Perhaps one of the most controversial and yet undeniable reasons for the dominance of psychopharmacology is the corruption of psychiatry by the drug industry. Pharmaceutical companies and scientists, physicians, and health policy makers harbor intimate relationships, largely of financial nature. Over a fifth of the funding received by the American Psychiatric Association, which oversees and publishes the DSM, comes from drug companies. In the second part of her two-part *The New York Review of Books* article, “The Illusions of Psychiatry,” Dr. Angell expands on this:

The drug industry, of course, supports other specialists and professional societies, too, but Carlat [the psychiatrist who wrote the book *Unhinged*] asks, “Why do psychiatrists consistently lead the pack of specialties when it comes to taking money from drug
companies?” His answer: “Our diagnoses are subjective and expandable, and we have few rational reasons for choosing one treatment over another.” (Angell, 2011b; emphasis added)

It makes sense that the drug industry would have interests in taking advantage of the uncertainty surrounding psychiatric diagnoses and their pharmacological treatments; the ambiguity offers the drug industry desirable wiggle room to inject their influence. This influence is not just with money, but people, too. Dr. Angell cites that, at the time she was writing, 56 percent of American Psychiatric Association (APA) members disclosed significant industry conflicts of interests (Angell, 2011b). That means over half of APA members—the authority of psychiatry and decision makers on psychiatric diagnoses, their criteria, and their suggested treatments—are inherently and intentionally biased toward the interests of psychopharmaceuticals.

These biases infiltrate nearly every topic that has been discussed thus far. For example, as Robert Whitaker and Lisa Cosgrove, fellows of the Edmond J Safra Center for Ethics at Harvard University, point out in their BMJ article “Corruption impairs discussion on long term use of psychiatric drugs,” “results from longer term government funded studies of psychiatric drugs have often been reported in a manner that protects psychiatry’s guild interests, rather than being consistent with the dictates of good science” (Whitaker & Cosgrove, 2015). There are dozens of examples of skewed research and intentionally-crafted and disproportionately-represented of positive results. Further, studies on pharmacology are disproportionately funded as compared to studies on alternative treatments. Research is just one of many areas that these conflicts of interest influence. This institutionalized bribery from the pharmaceutical industry ingrains science and medicine with a tremendous bias towards a highly subjective (corrupted) approach to diagnosis criteria and highly biological (pharmacological) approach to treatment.

(3) Lack of Resources

In part as a result of and in part independent from this corruption, a lack of resources also appears be a huge factor in why psychopharmacology is so prevalently the treatment of choice. This lack of resources manifests in a few forms: shortage of trained professionals (psychiatrists, psychologists, doctors); shortage of funding; and shortage of alternative treatments.

Shortage of human resources.

Although a skilled nursing facility, by definition, implies fewer doctors and more responsibility delegated to nurses, a skilled nursing facility is still expected to have enough trained resources to support its patients’ medical needs. At TCC, for the 559 beds (excluding the developmental disability speciality hospital), there are six full-time physicians—three infectious disease physicians and three internal medicine/geriatric physicians—leaving each physician with about 93 patients. Very few of TCC nurses are certified psychiatric nurses, or Psychiatric Mental
Health Advanced Practice Registered Nurses. In addition, to my knowledge, there are only two psychologists for the 559 beds. One of these is only at TCC for 12 hours a week and works exclusively with the Huntington’s patients (50 beds). The other psychologist is also contracted, though works at TCC full-time, but works primarily with the HIV/AIDS unit (~150 beds), as well as somewhat with the Huntington’s unit. This leaves the remaining units (Skilled Nursing Facility/Geriatrics, Sub Acute Rehabilitation)—that is, 359 beds, and 252 individuals with diagnosed mental disorders (Fig. 2)—without a primary psychologist at all, a number that seems unreasonably high and indicates a huge unmet need.

Finally, there is only one psychiatrist for the entire facility, who is only on-site 3 days a week for about 4 hours each (12 hours / week). This means that this one, part-time psychiatrist oversees all 339 patients with prescribed psychotropic medications. If she were to see each of these patients just once a month during her 12 hrs/wk, she would have a mere 8.5 minutes per patient, which does not include the time needed for walking between patients, finding patients, consulting with primary physicians and/or nurses, charting, or breaks. Despite the fact that the actual scenario may vary (e.g. not every patient needs to be seen as frequently, and some patients need to be seen more frequently and require more time during visits than others), in no scenario is this one psychiatrist adequate for filling TCC’s need. When I asked, the psychiatrist explained that, on a typical day, she sees about 20 patients. Thus, even in reality, the psychiatrist only has 12 minutes per patient to walk to the patient’s room, find the patient, visit with the patient, take notes, and consult the doctor and nurses. To make matters worse, finding patients is not as efficient as one might hope and expect. This was noted several times in my conversations and five shadowing experiences with the psychiatrist (i.e. “I waste so much time walking back and forth, trying to find patients or having to come back because they’re not in their room”). This is also noted in many of the psychiatry notes, which include the statement “greater than 50% of the visit time was spent providing counseling and/or coordination of care while on this patient’s unit/facility.” If we are going off of our previous estimate, this means that often times more than 6 of the 12 minutes (50%) that the psychiatrist has per patient is spent doing something other than assessing the patient’s need for psychiatric medication. While I am not a psychiatrist myself and thus cannot comment with any sort of expertise on the matter, my semi-educated layperson perspective would assume that 6 minutes is not a realistic amount of time to successfully receive a full enough picture of a patient’s psychiatric state to make a decision about controversial medications that drastically change the patient mentally and physically.

**Shortage of funding.**

This shortage of human resources is primarily a result of a shortage of funding. On one hand, the hospital does not receive enough funding to employ as many psychologists and psychiatrists as it really needs, which leaves the few psychologists and psychiatrists stretched tremendously thin and doing what they can with what they have, but unsurprisingly not without
flaws. More than that, funding from insurance companies is biased toward psychopharmacology and against ‘talk therapy.’ Dr. Angell offers an example of this in her article “The Illusions of Psychiatry:"

Carlat treats his patients only with drugs, not talk therapy, and he is candid about the advantages of doing so. If he sees three patients an hour for psychopharmacology, he calculates, he earns about $180 per hour from insurers. In contrast, he would be able to see only one patient an hour for talk therapy, for which insurers would pay him less than $100. (Angell, 2011b)

This is perhaps yet another example of how far the pharmaceutical corruption in psychiatry reaches. Regardless, it is clear that money, yet again, greatly influences the prevalence of psychotropics and, more importantly, the quality of patient care. This problem is likely not one that can be solved at the hospital level, but rather at the state and federal level.

**Shortage of alternative treatments.**

With such a shortage of human resources and funding, it is not surprising that there is a shortage of alternative treatments, i.e. psychological services, such as cognitive behavioral therapy or group therapy. This shortage is clear at TCC, as demonstrated in Cersonsky’s 2015 report. In 2015, only about 20% of patients taking psychotropic medications had a psychology visit in the past year (Cersonsky, 2015). This means that the vast majority of patients are being treated with only psychotropics, despite the innumerable psychiatrists, psychologists, and scientists across the country that defend that mental illness treatment should, more often than not, be a combination of psychotherapy and psychopharmacology at the very least. Likewise, group talk therapy options are limited mostly to one substance abuse group, which I attended and helped expand throughout this summer. The group is held weekly and has shown some, but minimal, success. The reason for this shortage in alternative treatments is not because they do not work, as research has shown that they are helpful. Rather, the reason is likely, again, a result of the lack of personnel and funding. How can these alternative treatments flourish when the human resources, and likewise, funding that they require, are not available?

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Together, all of these reasons set a perfect stage for psychopharmacology to dominate. Imagine: even if a psychiatrist wanted to give talk therapy, the psychiatrist does not really have time to do so thoroughly in the 6 minutes that s/he has allotted to interact with the patient. Moreover, s/he is financially motivated by insurance companies to prescribe a psychotropic drug instead of performing talk therapy. S/he is stretched incredibly thin, which only fosters an environment that encourages acting towards self-interest and simply medicating rather than using the alternative (talk therapy), as the latter by definition requires human resources to perform and thus adds what could be viewed as an additional burden for the psychiatrist and other healthcare providers.
Moreover, due to the lack of psychologists available, referring the patient for psychotherapy is increasingly difficult and inaccessible. Likewise, the entire psychiatric industry champions more prescribing of psychotropics, which is backed up further with biased research.

I’ve painted here a very pessimistic picture of the reality, one that even I admit is not always as negative as I’ve here described. As I said above and will say again, these psychotropic drugs really do help so many people. However, that does not stand as an excuse for these huge flaws in psychiatry. In fact, the claim that psychotropic drugs help many is actually independent of these flaws, in that, if these flaws were fixed, psychotropic drugs would still be around and, most importantly, they would still be there for the people that they truly help.

**Specific Populations & Cases**

Before discussing alternative treatments and solutions, I want to put our discussion in the context of a few more specific cases and unique patient populations at TCC.

**Population A: Huntington’s Disease**

Huntington’s disease (HD) is an inherited genetic neurodegenerative disorder. HD is often uniquely characterized by the onset of involuntary, choreic (dance-like) movements and, more generally, by the deterioration of a variety of physical, psychiatric, and cognitive abilities. HD is notably—and sadly—a slow-progressing disease; symptoms typically appear between the ages of 30 to 50 and worsen over a 10 to 25 year period. Because of the nature of Huntington’s disease and its progression, many individuals with HD lose the ability to communicate. As cliché as it sounds (and I realize stating that only makes this sound all the more cliché), it was truly an eye-opening experience to witness what the real impact of not being able to communicate is.

Of particular interest to our present discussion are the psychiatric components of HD, which, not unlike many components of HD, are mostly not yet fully understood (Paulsen et al., 2001; Julien et al., 2007; Jauhar & Ritchie, 2010). As TCC’s HD neurologist stated:

- There is no right answer regarding psychotropic medication in HD. Due to a lack of randomized controlled trials and guidelines in this orphan disease, physicians follow a practice pattern. Overall, they may be useful when behavioral problems predominate with neuroleptics and I do prescribe SSRIs in general due to the possibility of depression.

For these reasons and others, patients with HD present unique challenges to psychiatrists and psychologists. Yet, despite these challenges, patients with HD are prescribed significantly more psychotropic medications, especially antipsychotics, than any other unit at TCC (Fig. 5). Let’s explore some of the challenges and their consequences through a few patient cases.
**Case 2: NO**

NO is a 44-year-old male diagnosed with Huntington’s disease, as well as major depressive disorder, psychotic disorder with delusions, anxiety disorder, and bipolar disorder. He is prescribed Remeron and fluoxetine (two antidepressants), Klonopin (an anxiolytic), and haloperidol (an antipsychotic). During my time at TCC, NO was an especially notable case due to his uncontrolled obsessions and compulsions for showering. Because NO has Huntington’s disease, this is a major concern, as his motor functioning is severely disabled, which leaves him as a high fall risk. Therefore, he must be accompanied any time he showers, which means one of the registered nurses (RNs) or Certified Nurses Aides (CNAs) must take extra time to give him multiple showers. To provide an idea of what this looks like, one morning report, NO was noted to have gone to the bathroom to take a shower six times between the hours of 12:00 and 4:00 AM. This has indeed, at least on one occasion, led to a fall, which resulted in a minor injury. As a solution, many of the doctors, nurses, and the psychiatrist suggested titrating up his antipsychotics. However, this was not well-received by his sister, whom makes his medical decisions and is very involved in his care. There was much back and forth between changing of his psychotropic medications and his sister’s resistance.

Both perspectives—that of the healthcare providers and that of the sister—have very valid concerns. The sister is concerned about her brother’s quality of life, in that she doesn’t want all of the negative side effects discussed above—for example, oversedation, even more psychiatric symptoms, etc.—to occur. This is valid, especially considering that NO is on four psychotropic medications already. However, when the situation is discussed with her, she does not to seem to fully understand the severity of NO’s symptoms and the level of care they are requiring. On the other hand, the healthcare providers are concerned about the danger that NO is in when he showers and the time that these showers require of the RNs and CNAs. However, they appear to perhaps be discounting the potential side effects that increased antipsychotics may create, and the added risk that comes with not being able to measure these side effects as well if and when they do occur, due to NO’s hindered ability to communicate.

The danger of discussing the psychiatric and cognitive effects of Huntington’s disease without understanding them is that we can too easily and sometimes prematurely use them to invalidate an individual with HD, especially once that individual has lost the ability to communicate and cannot express his or her own thoughts. NO is on four psychotropic drugs. Four. Four drugs that have huge risks for causing more harm than benefit are prescribed to a patient in which, for the most part, the consequence of these drugs is incredibly difficult to assess.
Case 3: UD

UD was the perfect representation of how difficult it is to understand the psychiatric components of Huntington’s disease. I met Ms. UD one day on the patio. The patio was lively and it was a beautiful day, so Dr. Lechich brought Ms. UD out to enjoy the experience, too. Before he introduced me, Dr. Lechich told me to be careful and perhaps not get too close, as Ms. UD had been known to be volatile sometimes. I noted this and sat down to talk to her. Immediately, it was clear that his instruction would be difficult to follow. Ms. UD’s speech, not unlike many individuals with Huntington’s disease, was incredibly difficult to understand—it was severely slurred and mumbled. Moreover, she spoke quietly and trailed off, which made her difficult to hear, especially with all of the other noises on the patio. If I wanted to continue the conversation, I had no choice but to lean in to even attempt to hear her and decipher what she was saying.

Even then, our conversation was going downhill. I could barely understand a word she was saying through the mumbling and slurs. I felt helpless and guilty, and I could tell she was getting frustrated, too. I didn’t know what to do, but I knew the last thing I wanted to do was to give up; I did not want to give up on her. I’d say, “Can you say that one more time?” and she’d grunt something out, and I’d look back helplessly. Finally, “one more time” became one time too many. Ms. UD swung and hit my head. I was caught completely off-guard. The director of the HD unit ran up and made sure I was ok and addressed Ms. UD. At that point, Ms. UD mustered up some sort of energy and yelled out, loud and clear, with some profanity, “she can’t understand anything I say.” The HD director took Ms. UD back to her room, and afterwards commented that Dr. Lechich should have never brought her out there.

I am not sure I agree. I think it was commendable of Dr. Lechich to bring her out there, and I’m really glad he did. It is so easy to blame Ms. UD for hitting someone, and it’s valid to do so. She hit someone. That is not acceptable. But what made me feel so unsettled was not so much that she hit me, but that she was so frustrated and felt so misunderstood and trapped, that she saw no other option but to resort to physical violence. Sure, she may have had some underlying psychiatric disorder, which may be a result of the Huntington’s disease. But regardless of if she did or if she did not, perhaps she was also just full of thoughts and desires to communicate them, and was simply unable to do so. We should not so quickly discount that, yet too often, we do. For example, the psychiatrist once remarked, “In Huntington’s, it's a little different because they lose totally the cognition at some point.” While it is known that HD can and often does have psychiatric and cognitive symptoms in addition to the motor symptoms, it is incredibly dangerous to generalize those symptoms for all patients with HD.

Regardless of the status of UD’s cognition and psychiatric state at the time, in neither case was the best solution to keep her in her room and away from anyone’s attempt to communicate with her. That decision is not in her best interests, just the best interests of those around her; that decision protects others’ quality of life at the expense of Ms. UD’s. Bringing her
out to a busy, noisy patio and leaving her alone with just one other person, which puts a lot of pressure on her to create conversation, may not have been the best solution. But it was something, and something is better than nothing.

**Case 4: TX**

If you know anything about patient TX, you know that, before she was a patient, she was a doctor—a pediatrician. And just about that quickly, you realize how cruel the irony of life is. Three years ago, Dr. TX was a walking and talking HD advocate. Now, she sits in her wheelchair daily, unable to walk, and more importantly, for the most part unable to talk. She comes off as very stoic and very unreachable. She is 50 years old, diagnosed with major depressive disorder and bipolar disorder, and prescribed clonazepam (an anxiolytic), Abilify (an antipsychotic), and sertraline (an antidepressant).

One of the other 2016 TCC interns, Jill, focused her project on the use of the Tobii Dynavox system ([www.tobiidynavox.com](http://www.tobiidynavox.com/)), a form of augmentative and alternative communication, with HD patients. This system is functionally a screen with which an individual interacts via eye gaze; one’s eyes function as the computer’s mouse. We were able to pilot the Tobii Dynavox system with Dr. TX. When we did, a whole other world was opened. We were able to communicate with Dr. TX. We were able to connect. We played Blackjack with her. She would stare at the screen, and then we’d hear it say, “Hit” “Hit. Hit. Hit”. We gave her another card. Aw, man, one too many—she lost the game... but she won the day. Dr. TX grinned her rare grin that, I swear, lit up the entire room. Later, we read the *New York Times* best selling novel “The Gene” to her, and her gaze would follow along as we flipped the page or looked up and back down from the book. We’d ask, “Can you hear us ok?” She’d look at the screen. “Yes. Ye-. Ye-. Yes. Ye-. Yes. Yes,” the machine would announce as she stared at it. She’d look back to us. We’d ask, “Are we reading too fast?” and hear, from the Tobii in response, “No. No.”

It was humbling to experience how much of Dr. TX was still there. But, it was saddening to realize how few people—doctors, psychiatrists, nurses—were able to experience that, too.

Without taking the effort to try to connect with Dr. TX, we never would have. As I reflect, among other things, this experience taught me how important it is for our healthcare system to build in time for a doctor to make this sort of effort, especially with HD patients.

**Case 5: IT**

Mr. IT is a 56-year-old male diagnosed with Huntington’s disease, anxiety disorder, bipolar disorder, and major depressive disorder. He is prescribed Clonazepam (an anxiolytic) and Citalopram (an antidepressant). Mr. IT’s symptom presentation is somewhat unique, in that, he has very little chorea and instead has more hypokinesia (i.e. muscle rigidity and/or inability to produce movement), accompanied by myoclonus (spasmodic jerky contraction of groups of
muscles) in his extremities and jaw. Because of his myoclonus, especially, IT has a very difficult time communicating.

The first time that I really sat down and introduced myself to IT was during music therapy. I introduced myself, but IT had a hard time communicating back. The music therapist came over and asked if IT wanted to hear any specific songs. He told me that IT used to be able to choose more often, but has been having a lot more difficulty recently. He gave me some suggestions of what IT liked: Bon Jovi, Madonna, Shania Twain. I pulled out my iPad and showed IT a picture of Bon Jovi’s Livin’ on a Prayer. I asked if he’d like to listen to it, and after several seconds, he managed to say “sure.” The music therapist played the song and started singing. “Once upon a time not so long ago…” The other intern and I sang along, too. The three of us sang the first verse. When we got to the chorus, a fourth voice chimed in. “Woah, we're halfway there / Woah, livin' on a prayer / Take my hand, we'll make it I swear / Woah, livin' on a prayer.” IT sang the chorus perfectly, without a single stutter, smoother than me. He sang, and he smiled.

After that instance, I came back to visit IT several times more, and we were even able to have short conversations. One time, I showed him an image of Madonna’s Like a Virgin and asked him if he knew that song. After a few moments, he replied “A little bit.” Then, I showed him a picture of Madonna on my iPad: “Here’s what Madonna looks like today. What do you think?” Again, after stuttering a bit and working hard to get the words out, he said, softly, “She looks the same. Still young.” Then, I asked, “Do you want to see a picture of Shania Twain now?” I pulled up a picture. IT responded, “Nice. Still living.” When I said, “Man, she’s really pretty,” he responded, with a slight but notable smile, “yeah.” Another time, in trying to assess whether he would be able to point to things, I asked IT, “So IT, can you control your hands at all?” He said, with a bit of struggle and slur, “No. Do not.” When I would leave, I’d say, “Have a good day, IT.” And he’d whisper back, “You too.”

While I have no medical certification, my assessment is that IT’s mind is still very much there. He is acutely aware of his condition, as one of the psychologists remarked, an example of how dangerous it is to assume that HD always compromises cognitive abilities. On the outset, IT’s symptoms, such as loss of muscle control and the inability to communicate, are similar to many of the other individuals with Huntington’s. However, it is dangerous to assume the state of his or any patient’s cognition and psychiatry from their physique. Only by spending the time and putting forth the effort to communicate can the former be assessed. All it took was me making the effort to stop and listen, to say genuinely, as IT’s myoclonus caused his lip to shake and made speaking difficult, “it’s ok, take your time” and then to do just that—to wait patiently as he forms a response.
This common communication and connection barrier in HD exaggerated at least two of the flaws related to mental illness that we’ve discussed: the poorly understood biology and the lack of resources.

First, without communication, it is difficult for a patient to demonstrate or explain any alterations in emotion or cognition, and likewise it is also difficult for a doctor to identify any alterations. For example, it is difficult to tell if Ms. UD’s hit was a result of underlying psychosis, disinhibition, or personality disorder, or whether it was simply her attempting to communicate in the only way that she was physically able. It is difficult to say whether there is truly a disorder or ‘abnormality’ when we have such a narrow picture and pool of data. This makes diagnosis even more complex, as it is difficult to apply the methods and criteria to someone with severely compromised communication and motor functioning.

The communication barrier also intensifies the consequences of lack of resources. We already know that doctors and nurses are overbooked and understaffed, leaving quality care and thus these patients to suffer; recall the estimation above, that TCC’s psychiatrist has about 6 minutes per patient to interact with the patient and evaluate them. Despite the fact that the quality of this time can vary greatly from psychiatrist to psychiatrist, depending on how much effort is put forth to connect with and understand a patient, it is still safe to assume that quality will automatically decrease during a consultation with a HD patient, merely because the communication barrier inherently adds an extra demand for time. This means that, even if they are making their best effort to communicate and connect with a patient with HD, psychiatrists, doctors, or nurses will not be able to get as far with a patient with HD as they would with a patient who has full communication abilities. Likewise, this suggests that a psychiatrist, doctor, or nurse must make that much more of an effort than they do with other patients, which in turn makes it is even more likely that this effort won’t be made.

**Population B: Dementia and Alzheimer’s Disease**

Older adults are known to be especially vulnerable to the serious and adverse side effects of psychotropic drugs (Bulat et al., 2008; Carr, 2005; Grasso, Bates, & Shore, 2007; Lindsey, 2009; Mott, Poole, and Kenrick, 2005). As mentioned in the Introduction, global health agencies have issued warnings about the risks of prescribing psychotropic drugs to frail individuals, especially those affected by dementia. Guidelines recommend their use only in cases where the benefits clearly outweigh the risks. The number of patients on the dementia/Alzheimer’s floor\(^2\) who are prescribed psychotropics (68%) is higher than the TCC average (TCC total population, 58%) (Fig. 8). Moreover, 24% of this population is prescribed antipsychotics.

Antipsychotic drug use in elderly patients with dementia, in particular, is especially concerning, for several reasons. Historically, these drugs have been used as a chemical restraint

\(^2\) This floor/unit does not represent all patients that are diagnosed with dementia or Alzheimer's at TCC. Therefore, these numbers are likely low in their projections.
in this population, i.e. to control the sometimes erratic behaviors that dementia patients present. This is clearly an extremely unethical practice. Moreover, as writer Brendan Smith reveals in his 2012 *American Psychological Association* article “Inappropriate Prescribing,” “…evidence [regarding the benefits of antipsychotic drugs] is much less conclusive for treating psychotic symptoms in patients with dementia” (Smith, 2012). Antipsychotics have also been associated with increased mortality in older adults with dementia (Maust et al., 2015). Nevertheless, as Smith cites:

> One in seven elderly nursing home residents had Medicare claims for antipsychotic drugs in 2007, and 83 percent of those claims were for off-label uses, according to an audit last year by the U.S. Department of Health and Human Services. The federal investigation also found that more than one in five Medicare claims for antipsychotic drugs didn't comply with federal guidelines prohibiting unnecessary or excessive medication of nursing home residents. (Smith, 2012)

This continued concern is echoed by the Texas Department of Aging and Disability Services (2016): “despite the Food and Drug Administration’s warnings of increased mortality, the use of antipsychotics as a chemical restraint in nursing home residents who have dementia still persists.” For these reasons, the concerns surrounding psychotropics are even further heightened and require even more careful attention when treating patients with dementia.

**Population C: HIV/AIDS**

**Case 6: WT**

WT is a 50-year-old male with HIV, mild dementia, and schizophrenia, for which he is prescribed Abilify (an antipsychotic). WT’s defining characteristic is his humor; when you first meet him, and any time you see him thereafter, he will ask if you want to hear a joke and tell you one of the few that he has in his arsenal. WT speaks at a very hurried pace, stumbling and stuttering over his words, which can make it difficult to understand him. On the surface, it is easy to group WT with some of the other patients on the HIV/AIDS unit whom have dementia, and to assume that he’s not very oriented to reality and that his memory is unreliable. However, throughout the summer, I myself was put in my place to not make such assumptions—ever. Over time, I realized that WT consistently remembered my name. I realized that he told the same jokes over and over not because he forgot that he’d already told me them, but because he just didn’t know any others. I realized that his seemingly incoherent “ramblings” were not ramblings at all, but were in fact quite coherent. With these realizations, I developed strategies to use when talking to him, such as asking him to slow down and take his time. I would tell him that he didn’t need to rush to get things out, as I wasn’t about to leave him mid-sentence. When I’d say that, he’d do just what I asked, making a full and meaningful conversation possible.
I recall, on one occasion, WT asking if he could get his money. There were some complications and confusions with the situation, in which he didn’t have money or have access to it or something of the sort, as we realized after talking to WT’s Social Worker. While we didn’t know how to resolve the situation, we tried to give WT some response and explanation. He was clearly disappointed and, among other things, responded hopelessly with “but I’m a grown adult.” Through this statement, I was able to see what the core issue here is: WT feels stripped of his dignity, not because he doesn’t have his money, but because he is treated as though he doesn’t deserve it or other pleasures. He feels hopeless.

Another time, when one of the other interns and I were walking by WT’s room, WT called out our names. We learned that WT, who is wheelchair-bound, was taken out of his wheelchair and put into his bed every day for 2 hours a day. It made him really upset. He said things like “Shannon, I’m so lonely” and “I don’t know what to do.” We learned that, essentially, the reason this occurred was so that he wouldn’t disturb the nurses and others on the unit. He needed the time away to ‘destimulate.’ In a way, he was put in time out. While we were talking with WT, one of the CNAs walked by and said, “WT, quit bothering these girls!” to which he responded “they want to talk with me!” We confirmed.

I’ll admit: WT does talk a lot, and that can interfere with other patients’ quality of life and with clinicians’ ability to do their work. But perhaps the solutions that are being practiced currently, such as putting him in his bed for 2 hours a day, are not the best ways to tackle these challenges. Instead, perhaps he could be otherwise occupied, such as with a video that has good jokes, or reasoned with by simply talking to him like an adult. Just because someone like WT has mental and physical challenges that put a ‘burden’ on those around him does make it justifiable for those around him to treat him like a child and strip him of his dignity.

WT’s case, among others, showed me the importance of the attitude in patient care. For WT, the concern had nothing really to do with his psychopharmacological treatment. The concern had everything to do with the biases and stigma through which he was treated. So often, he was “listened to,” but not heard. He was often not taken seriously and not respected and dignified as a peer.

**Case 7: KW**

KW is a 55-year-old male with HIV, hepatic encephalopathy, generalized anxiety disorder, and paranoid schizophrenia. He is prescribed haloperidol and Abilify (two antipsychotics) and lorazepam (an anxiolytic). I first met KW while shadowing the psychiatrist (Appendix 2). During this visit, it felt very possible to connect to KW on a certain level and understand him. He was, for the most part, very aware, alert, and oriented (he knew where he was, what year it was, etc.), although not completely (for example, he didn’t correctly identify the psychiatrist).
A couple weeks later, we (the psychiatrist, another intern, and I) visited KW again. This time, he was very different. A few days prior, KW had gone to a CNA with a butter knife in his hand and said, “Make it easy for me, and end it right here.” He was put on one-to-one observation, which is basically when someone is assigned to sit with him 24/7 to assure his and others’ safety. His psychiatric symptoms were clearly much different this visit; as the psychiatrist put it, “Last time, he was organized. This time, he’s going from one idea to another.”

Despite how disorganized and somewhat delusional his words were, there was still meaning and a theme in his words. For example, here are some of his statements:

“So many people here want to fight me” ...

“I decided not to take [the medicine] because I don’t wanna stay here because so many people want to kill me and I don’t want to be the last person on Earth to die.” ...

“When I take the medication, it adds more time.” ...

“I’ll never get out of here, dead or alive.”

KW clearly was very concerned about death and felt attacked or threatened. While these concerns may not be rational in the context of the reality that you or I experience, they are completely rational in KW’s reality; for him, these feelings of tension and anxiety are very, very real. It’s important for us to validate that experience. However, sometimes, these concerns were not taken that seriously. In the visit, there was little attempt at trying to explore why he was feeling suicidal, why he felt so many people were out to get him, or why he thought the best solution was to not take his medicine. I recognize that it may be senseless to try to rationalize with the irrational; however, I think it is important to respect and care, and not just assess. I think the psychiatrist tries her best, but as mentioned above, does not have the time or monetary support to give these 100%. Yet still, not once did a psychologist come to visit him in this time. Rather, he was given one-to-one, essentially someone to assure he didn’t cause trouble and to keep a direct eye on him, but not intended to talk with him; she just sat there with a clear look of boredom on her face. The only consideration for helping KW was more medication; titrating back up his Ability, which had recently been reduced from 30 mg to 20 mg in an attempt at a gradual dose reduction. The possibility that Villain's symptom presentation following the dose reduction was a result of withdrawal (a valid and scientifically-supported possibility) not unmanaged schizophrenia was not considered.

While KW’s case can serve as an example of the flaws in some attitudes toward people with mental illnesses, KW’s case can also serve as an example of the triumphs of others. During the time that all of this was happening, KW’s Social Worker did something that I found really respectable: he bought KW a hand radio. If there was one thing that remained consistent with KW, it was that music was very important to him. From our first visit on, KW mentioned his music. In his words: “It makes me feel good.” When the psychiatrist asked to turn the music off, KW mentioned that the music helps drown out the voices; he couldn’t hear or concentrate without his music. KW’s Social Worker listened to and heard KW when KW said that the music
drowns out the voices and makes him feel good. KW’s Social Worker helped solve the problem not by prescribing KW medication, but by giving KW a radio.

Solutions

I have talked a lot about the psychopharmacological treatment option. Let us now, instead, consider the alternatives, the perspectives that have not yet been represented here.

Alternative Therapies

There are several types of alternative therapies that I could discuss, such as psychoanalytic, psychodynamic, behavioral, and cognitive behavioral therapies. While these are all important and should be considered as viable treatments offered to individuals with mental illness, I will instead focus on a few select approaches, which are primarily focused on holistic recovery rather than symptom treatment. Journalist Benedict Carey explores a few programs that are doing just this in his *New York Times* article “An Alternative Form of Mental Health Care Gains a Foothold” (Carey, 2016). Here, Carey discusses the Hearing Voices Network, or HVN (hearingvoicesusa.org) in Holyoke, MA, a group for individuals who, as you may have guessed, hear voices. More than that, though, HVN is a group “in which members help one another understand each voice, as a metaphor, rather than try to extinguish it.” For example, one member, Sarah, has heard the voice of a child crying for years. Instead of medication, the HVN offered an alternative solution:

In the group, other members prompted her to listen to the child’s cries, to ask whose they were, and why the crying? Those questions led, over a period of weeks, to a recollection of a frightening experience in her childhood, and an effort to soothe the child. This altered her relationship with the voice, she said, and sometimes the child now laughs, whispers, even sings. (Carey, 2016)

In addition to the HVN, Carey also covers the Open Dialogue program (http://www.dialogicpractice.net/open-dialogue/about-open-dialogue/), an alternative approach to treating psychosis that “involves a team of mental health specialists who visit homes and discuss the crisis with the affected person—without resorting to diagnostic labels or medication, at least in the beginning” (Carey, 2016). In fact, the first study of the Open Dialogue program in the United States, “Adapting Open Dialogue for Early-Onset Psychosis Into the U.S. Health Care Environment: A Feasibility Study,” was published earlier this year in *Psychiatric Services* (Gordon et al., 2016). Carey summarizes the study well: “The results are encouraging: Nine of 14 young men and women enrolled in the program for a year after a psychotic episode were still in school or working” (Carey, 2016). Both of these programs offer progressive approaches to helping individuals with mental illness.
The city of Geel in Belgium offers yet another shining example of successful alternative treatment for mental illness. For centuries, residents of Geel have accepted individuals with mental disorders into their homes and cared for them. The history, success, and greater potential of this unique haven for individuals with mental illness was discussed in the NPR Invisibilia special “The Problem with the Solution” (Miller & Spiegel, 2016). In her NPR Shots article covering the podcast, Angus Chen introduces how Geel works:

...the program typically selects patients with severe mental illness or cognitive disabilities who have difficulty living independently. In 2003, almost half of the town's 516 boarders had a cognitive disability, and over 20 percent carry a diagnosis of schizophrenia or other psychotic disorder, according to research by Jackie Goldstein, a professor emeritus of psychology at Samford University. (Chen, 2016)

The Geel community completely integrates their boarders into the community, providing them with social opportunities and meaningful work in the community. Like with Open Dialogue and Hearing Voices Network, the people of Geel “have not only accepted the eccentric or disruptive behaviors of the boarders but have come up with creative [and practical] ways to help boarders and residents manage them” (Chen, 2016). For example, when one boarder, Ennekans, hallucinated lions coming through the walls, his host Smit “would pretend to chase the lions away. ‘And that would work every time,’ Smit says” (Chen, 2016). For over 700 years, Geel has been successfully treating people with mental illness in this way.

Admission of the Downfalls

Of course, these alternative treatments are not perfect. For example, Chen recounts some of the challenges that the aforementioned host Smit has experienced:

...Toni Smit and Arthur Shouten say that living with Ennekans was rough at the start. Ennekans became deeply attached to Smit. "If it were up to [Ennekans], he would be hugging and kissing me all day," Smit says. He showered her with such affection, bringing her flowers, little kisses, linking arms with her on walks, that it began to interfere with Smit and Shouten's marriage. "You couldn't even give each other a hug or Luc is standing behind us," Shouten says. Wrinkles like this are common, according to the couple.

One boarder used to lock Smit and Shouten out of the bathroom to furiously wash his hands, and another used to struggle to sleep because he saw lions coming out of the walls. "He was really dementing," Smit says. But that doesn't affect the way they see their boarders. Like many hosts in Geel, they accept that this is simply who their boarders are. It's not abnormal or something they need to change. "It's just normal life," Shouten says. (Chen, 2016)
These programs do not claim to ‘cure’ the participants or to take away the challenges that their disorders bring, which some may critique. Carey notes some further critiques in his New York Times article, writing that:

Some psychiatrists are wary, they say, given that medication can be life-changing for many people with mental problems, and rigorous research on these alternatives is scarce. “I would advise anyone to be carefully evaluated by a psychiatrist with expertise in treating psychotic disorders before embarking on any such alternative programs,” said Dr. Ronald Pies, a professor of psychiatry at SUNY Upstate University, in Syracuse... (Carey, 2016)

These worries are completely valid and incredibly important. The last thing anyone would want would be for one of these programs to make matters worse for an individual, or to put anyone in danger. However, these programs also acknowledge this, and recognize that they may need to be paired with pharmacological interventions. In the case of the Hearing Voices Network, “many people who regularly attend have prescriptions, but many have reduced dosages” (Carey, 2016).

Many of the individuals in the Open Dialogue program also continue on psychotropic medications. In Geel, every boarder sees medical professionals at Geel’s psychiatric hospital, which manages the boarder program and where the boarders receive treatment (such as psychotropic medications) and evaluations. Still, it is accurate to say that there are many instances where these alternative treatments, by themselves, are not perfect. But in the same vain, neither are psychotropics, and yet we see how prevalent they are...

Attitude and Stigma

When it comes down to it, what is most remarkable about Geel, about Open Dialogue, about Hearing Voices Network is the attitude of those involved: they treat people with mental illnesses as they treat any of their fellow men and women, as humans, with dignity and respect, and without stigma. Instead of coming from a position of non-acceptance, invalidation, and repudiation, these solutions come from a position of acceptance, tolerance, and inclusion. Here lies the truest failure of psychiatry: in moving its focus onto medication and ‘symptom treatment,’ it has lots its focus on humanity. When Hearing Voices Network member and now leader, Ms. White, told her psychiatrist that “the drugs just made [her] feel worse,” her psychiatrist told her that “if [she] didn’t take the meds, [her] brain would become more and more damaged” (Carey, 2016). When another HVN member and leader, Marty Hadge, was taking Thorazine, he recounted that “‘about all [he] could do [was] lie on the couch, and the doctors would say, ‘Hey, you’re doing great — you’re not getting in trouble!’” For White and Hadge, ignoring the adverse side effects that these drugs had on their personality and identity was the equivalent of ignoring the struggle that they faced every single day. But that’s exactly what doctors did. Despite the side effects they were experiencing, doctors just kept prescribing. Yet another Hearing Voices Network member, Sarah, whom I mentioned earlier “was told [she] was
a ticking time bomb, that [she]’d never finish college, never have a job, never have kids, and always be on psychiatric medication” (Carey, 2016). Doctors diagnosed her with borderline personality disorder and “put [her] on medications that had severe side effects” (Carey, 2016). However, with the help of the Hearing Voices Network, Sarah is now set to graduate from college with honors. Sarah reflected on the HVN group, “‘That is the way it works here. ...In the group, everyone’s experience is real, and they make suggestions based on what has worked for them.’” Sarah’s reflection identifies the key to these alternative treatments: in them, “everyone’s experience is real,” everyone’s experience is valid. Members are not shamed or babied because they have a mental illness. They are not treated as less-than or outsiders. They are just treated as human. As Jacques-Joseph Moreau reflected on Geel in 1845, “to them, treating the insane, meant to simply live with them, share their work, their distractions… In a colony, like in Geel, the crazy people ... have not completely lost their dignity as reasonable human beings" (as cited in Chen, 2016). Perhaps the core of the problem is not so much the medications themselves, but instead psychiatry’s blind allegiance to them, even at the expense of patients’ humanity; psychiatry too often neglects to acknowledge that “the overriding goal of ‘less symptoms’ does not necessarily translate into [the] ethic of maximizing the individual’s growth” (Levine, 1997, p. 201). Psychiatry, society even, too often fails to prioritize the complexity of what it means to have a worthwhile life. However, this perspective can so easily change, if only we are willing; it is arguably the only ‘fix,’ among the many discussed, that we can each individually do ourselves—perhaps even the ‘fix,’ among the many discussed, that we each must do ourselves before any others can truly be set into motion.

Practical Solutions

In writing this report, I felt it was most important to have a more removed conversation about this topic. I felt it more important to inspire reflection and thought, than offer practical advice that may be more difficult to implement. However, I’d still like to offer some practical ideas that could be applied directly at TCC. There is no doubt that these reforms will pose great challenges and take enormous efforts, but the alternative begs for sacrifices even greater.

These changes could include:

(1) **Improving inter-staff communication via patient behavioral mapping**: Primary doctors, psychiatrists, psychologists, and nurses should have the tools necessary for seamless communication, so that they all, especially psychiatrists who are not with the patient as often, can receive the most full picture and understanding of the patient before making decisions regarding their treatment (especially their psychotropic prescriptions). While at TCC, on a few occasions, I saw signs at certain nursing stations with instructions regarding “psychotropic notes.” This suggests that some sort of communication tool has attempted to address this need for
improved communication. However, when looking at the notes on TCC’s SigmaCare electronic medical record system, I found that this ‘psychotropic notes’ tool for communication between healthcare providers was often not used and thus apparently ineffective. This could perhaps be reformed by improving the process on SigmaCare, making it more intuitive and convenient to use. This could also mean integration of a more organized and efficient system into SigmaCare. Some ‘behavioral monitoring and mapping’ tools that could be used as a model can be found through the ‘One A Month Campaign for Reducing Antipsychotic Use’ offered by the Texas Department of Aging and Disability Services (2016), including this “Antipsychotic Medication Tracking Form” (http://www.tmfqin.org/Portals/0/Resource%20Center/Nursing%20Home%20Quality%20Improvement/Reducing%20Antipsychotic%20Medication%20Use/Antipsychotic%20Medication%20Tracking%20Form_final.xlsx).

(2) Modifying and requiring relevant healthcare provider training: We can modify and require practitioner and healthcare providers training to address (1) misconceptions about mental illnesses and their treatment, (2) practical strategies for providing compassionate care for those with mental illness, and (3) standards for communication about patients taking psychotropic medications. Educational resources for such goals can also be found through the aforementioned resources offered by the Texas Department of Aging and Disability Services (2016) as well as many other places.

(3) Implementing alternative treatments: As expanded upon thoroughly above, we can implement alternative treatments for psychiatric illnesses that presently do not exist, including psychodynamic, behavioral, cognitive behavioral, group, and holistic therapies. We must stop regarding psychotropic drugs as the saving grace, the best treatment for mental illness or emotional distress.

(4) Hiring more trained psychiatric healthcare providers: At the hospital level, we must hire more psychiatrists and psychologists to properly address the needs of TCC’s patient population. This must be accompanied by funding of these additions at the corporate, state, and federal level.

(5) Reforming insurance coverage: On more national level, we must reform the process by which insurance covers psychiatric services, expand insurance coverage for talk therapy and alternative therapies, and decrease the bias toward pharmacological intervention. This will allow healthcare providers to have a more objective and unbiased approach to their treatment decisions, and to spend more time communicating with each patient and following up with each of them regularly.

(6) Better regulation of the pharmaceutical industry: As also explored deeply above, conflicts of interests in so much of psychiatry need to be decreased and regulated.

(7) Balancing research funding: We must balance the amount of research on alternative therapies with the heavy body of pharmacotherapy research, accommodating and allocating
funding and support as needed. The results of this research should in turn be equally represented in clinical education.

(8) **Optimizing the psychiatrist’s work-flow:** We can trim the fat of the psychiatrist’s typical day, by decreasing the amount of time spent searching for patients or walking across TCC and replacing that with more time spent with the patients. This can be easily achieved by modeling some of the other specialties, such as TCC’s endocrinologist whom we shadowed: The psychiatrist can be given a part-time office to use in TCC, and the patients whom are capable can be brought to this office for their visit. The psychiatrist can then visit patients who are not capable of being brought to the office before or after. Instead of sending the psychiatrist the list of patients on the morning of, the full list of patients can be finalized the day before. For those whom the psychiatrist must visit at bedside, the list can organized logically by proximity. Nurses can be given this list, too, each morning and help assure patients are in their rooms at the designated time period during which the psychiatrist is expected.

(9) **Adopting a compassionate, open, accepting, dignifying attitude:** Out of all of these solutions, it is the attitude, set by Geel, by the Hearing Voices Network, by the Open Dialogue, that is most important for TCC to adopt.

For LN, this means exactly what Dr. Luong fought for: an idea that is non-pharmacological. It means not viewing his incessant calls to 911 as a burden and annoyance, but instead part of life, part of who he is, and in turn, trying to find ways to help him cope with the symptoms that are causing this behavior.

For KW, perhaps this means listening to his delusions and, instead of brushing them off, responding with concern and helping him to work through them or find a way to handle them. This means letting him know that his delusional experiences and feelings are valid. This meant giving him a personal radio. Perhaps this means, when trying a gradual dose reduction, not automatically assuming that the symptoms that come as a result are unkept disorder, but instead are perhaps symptoms of withdrawal, and then helping him find an alternative solution to coping with them.

For NO, this means finding a way that allows him to fulfill his obsessions with showering safely. This means perhaps first sitting down with him, patiently attempting to communicate, and understanding what exactly it is about showering he obsesses over. Is it that he constantly feels dirty? Is it the feeling of water running on his skin? Is it something else?

For IT and TX, this means being patient and making the effort to communicate, to use the Tobii Dynavox system.

For UD, this means listening. This means not responding with “she shouldn’t be out here in the first place,” but instead trying to work with her. This means not giving up.

For WT, this means being patient and asking him to slow down, so that you can hear what he’s trying to say through his stutter. This means not confining him to his bed for two hours a day. This means leveling with him and treating him as an adult.
For so many of these patients, this simply means listening. Truly listening. Truly hearing what these individuals are saying. Truly seeing them for who they are and meeting them where they are.

**Epilogue: Self-Reflection**

The stories told here were just a few of the many lives that I had the privilege of hearing about, experiencing, and being a part of during my summer at Terence Cardinal Cooke. Though I know it may be hard to believe, considering this report’s enormous length, these reflections represent only a snippet of the wealth of wisdom and growth I gained. To include them all would have been far too ambitious of a feat. While this report positively does not translate my full experience, I hope it is at least able to convey something useful and important to whomever reads it.

Life is fleeting, and death is beautiful. I will forever cherish everything that these incredible lives have taught me.
References


Figures & Appendices

Figure 1.

Comparison of each mental disorder category from 2015 and 2016 data, as a percentage of the total population of TCC.

*All 2015 data obtained from Censony, 2015.*
Figure 2.

Comparison of each mental disorder category from 2015 and 2016 data, as a percentage of the total population of each unit.
Figure 3.

Visualization of the number of mental disorder diagnoses per individual from 2016 data, as a percentage of the total population diagnosed with mental disorders.
Figure 4.

Comparison of all psychotropic drugs (excluding stimulants and antimanics) from 2016 data, as a percentage of the total population of TCC.

* This data does not include Antimanics (Mood Stabilizers) and Stimulants.
Figure 5.

Comparison of all psychotropic drugs (excluding stimulants and antimanics) from 2016 data, as a percentage of the total population of each unit.
Figure 6.

Visualization of the number of prescribed psychotropic medications per individual from 2016 data, as a percentage of the total population prescribed psychotropics.

* This data does not include Antimanics (Mood Stabilizers) and Stimulants.
Comparison of select psychotropic drugs—‘antipsychotics’ and ‘anxiolytics and antidepressants’—from 2015 and 2016 data, as a percentage of the total population of TCC.
Figure 8.

Visualization of all psychotropic drugs (excluding stimulants and antimanics) from 2016 data, as a percentage of the total population of 7H (dementia/Alzheimer’s unit).

* This data does not include Antimanics or Stimulants.
Appendix 1.

Diagnoses were organized into categories, which are detailed in this Diagnoses Index. (Modified from Cersonsky, 2015)

<table>
<thead>
<tr>
<th>#</th>
<th>Diagnosis</th>
<th>ICD-9</th>
<th>ICD-10</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>1</td>
<td>All Mental Disorders</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>2</td>
<td>Episodic Mood Disorder</td>
<td>296.9, 296.90, 296.99</td>
<td>F39, F34.8-.9, F06.30-.32, F06.34,</td>
<td>Applies to mood swings; symptoms include agonistic behavior, appropriate affect, blunted affect, blunting of mood, complaining of feeling unhappy, crying associated with mood, cyclic mood swings, despiritment, disturbance in mood, diurnal variation of mood, ecstasy, elevated mood, emotionally cold, emotionally distant, euphoria, euthymic mood, faddy behavior, feeling of failure, feeling abandoned, feeling angry, feeling emotionally hurt, feeling mixed emotions, feeling of discouragement, flat affect, hyperirritability, hypomanic mood, incongruity of mood, indifference, mood anorexia, mood disorder, mood disorder in full remission, mood disorder with manic features due to general medical condition, mood sing, mood swings, moody, non-delusional perplexed mood, over-optimism, physiological disturbance associated with mood, pleasurable affect, rebound mood swings, restricted affect, right hemispheric organic affective disorder, seasonal affective disorder, seasonal variation of mood, sensitivity, severe mood disorder with psychotic features, mood-incongruent, sublimation, temperamental, unpleasurable affect, unpredictable in mood, variability of mood, volatile mood</td>
</tr>
<tr>
<td>3</td>
<td>All Bipolar Disorder</td>
<td>296.0-2 96.6</td>
<td>F25.0, F30.10-.13, F30.2-.4, F31.0, F31.2, F31.10-.13, F31.30-.32, F31.4-.5, F31.60-.64, F31.70, F31.73-.78, F32.0-.5, F32.9, F33.9, F33.0-.3, F33.41-.42</td>
<td>A mental illness that brings severe high and low moods and changes in sleep, energy, thinking, and behavior</td>
</tr>
<tr>
<td>4</td>
<td>Bipolar - Unspecified</td>
<td>296.7</td>
<td>F31.9</td>
<td>Bipolar I Current NOS</td>
</tr>
</tbody>
</table>

(Modified from Cersonsky, 2015)
<table>
<thead>
<tr>
<th>5</th>
<th>Mental/Behavioral Problems</th>
<th>V40</th>
<th>F81.9, Z86.59, F48.9, Z91.83, F69</th>
<th>Not considered acceptable as a principal diagnosis as it describes a circumstance which influences an individual's health status but not a current illness or injury, or the diagnosis may not be a specific manifestation but may be due to an underlying cause</th>
</tr>
</thead>
<tbody>
<tr>
<td>6</td>
<td>General Mental Disorder</td>
<td>293.9, 294.8, V11, V40.2</td>
<td>F06.8, F06.0, F48.9, Z65.8, Z86.51, Z86.59, F29, F05, F03.90, F51.05, F42, F84.0, F03.91, F02.80, F90.1, F02.81, F28, F48.2, F01.51, F51.04, F44.5, F89, F90.9, F48.8, F07.89, F01.50, F90.0</td>
<td>Transient Mental Disorder NOS, Mental Disorder NEC, Personal History of Mental Disorder</td>
</tr>
<tr>
<td>Page</td>
<td>Condition</td>
<td>Code</td>
<td>Description</td>
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<td>-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------</td>
<td></td>
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<tr>
<td>8</td>
<td>Anxiety - Unspecified</td>
<td>F41.9, F41.8, F43.0</td>
<td>Apprehension of danger and dread accompanied by restlessness, tension, tachycardia, and dyspnea unattached to a clearly identifiable stimulus; apprehension or fear of impending actual or imagined danger, vulnerability, or uncertainty; feeling of distress or apprehension whose source is unknown; unpleasant, but not necessarily pathological, emotional state resulting from an unfounded or irrational perception of danger; compare with fear and clinical anxiety</td>
<td></td>
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<tr>
<td>9</td>
<td>Generalized Anxiety Disorder</td>
<td>F41.1</td>
<td>An anxiety disorder characterized by excessive and difficult-to-control worry about a number of life situations. The worry is accompanied by restlessness, fatigue, inability to concentrate, irritability, muscle tension, and/or sleep disturbance that lasts for at least 6 months</td>
<td></td>
</tr>
</tbody>
</table>
| 8    | Anxiety (NEC)                      | F06.4, F41.0, F40.01 | • Anxiety disorder due to a general medical condition  
• Anxiety disorder due to medical disorder  
• Organic anxiety disorder |
<p>| 11   | Adjustment Disorder                | F43.21, F93.0, F94.8, F43.22, F43.23, F43.29, F43.24, F43.25, F13.951 | Feeling of great sorrow, sorrowful response to an immediate cause; self-limiting and gradually subsides within a reasonable time, suffering and distress associated with loss |</p>
<table>
<thead>
<tr>
<th></th>
<th></th>
<th>F43.10, F43.12, F43.8, F43.20</th>
<th>A broad group of psychological disorders with abnormal eating behaviors leading to physiological effects from overeating or insufficient food intake</th>
</tr>
</thead>
<tbody>
<tr>
<td>12</td>
<td>Eating Disorder</td>
<td>307</td>
<td>F98.5, F50.00, F95.9, F95.0, F95.1, F95.2, F98.4, F51.9, F51.02, F51.03, F51.09, F51.01, F51.19, F51.11, F51.12, F51.8, F51.19, F51.3, F51.8, F50.9, F50.2, F98.3, F98.21, F50.8, F98.29, F98.0, F98.1, F45.41, F45.42, F63.3</td>
</tr>
<tr>
<td>13</td>
<td>Personality Disorder</td>
<td>301</td>
<td>F60.0, F34.0, F34.1, F21, F68.12, F60.89, F60.1, F60.3, F60.5, F60.4, F60.7, F60.2, F60.81, F60.6, F60.9</td>
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<tr>
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<td>A diverse category of psychiatric disorders characterized by behavior that deviates markedly from the expectations of the individual’s culture; this pattern of deviation is pervasive and inflexible and is stable over time. The behavioral pattern negatively interferes with relationships and work.</td>
</tr>
<tr>
<td></td>
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<td>A state, psychic and sometimes also physical, resulting from the interaction between a living organism and a drug, characterized by behavioral and other responses that always include a compulsion to take the drug on a continuous or periodic basis in order to experience its psychic effects, and sometimes avoid the discomfort of its absence. Tolerance may or may not be present. A person may be dependent on more than one drug.</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>The use of drugs, alcohol, or prescription drugs for a reason other than which it was intended or in a manner or in quantities other than directed</td>
</tr>
<tr>
<td>16</td>
<td>Depressive Disorder (NEC)</td>
<td>311</td>
<td>F32.9, F32.8, F33.40</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>Unpleasant, but not necessarily irrational or pathological, mood state characterized by sadness, despair, or discouragement; may also involve low self-esteem, social withdrawal, and somatic symptoms</td>
</tr>
<tr>
<td>17</td>
<td>Disturbance of Conduct (NEC)</td>
<td>312</td>
<td>F63.0, F63.1, F63.2, F63.3, F63.81, F63.89, F63.9, F91.1,</td>
</tr>
<tr>
<td></td>
<td></td>
<td></td>
<td>● Includes undersocialized conduct disorders (unaggressive and aggressive), socialized conduct disorder, disorders of impulse control NEC, mixed disturbance of conduct and emotions, other specified disturbances of</td>
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<tr>
<td>18</td>
<td></td>
<td></td>
<td>A major psychotic disorder characterized by abnormalities in perception or expression of reality. It affects the cognitive and psychomotor functions. Common clinical signs and symptoms include delusions, hallucinations, disorganized thinking, and retreat from reality</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th></th>
<th>Delusional Disorders</th>
<th>297</th>
<th>F22, F23, F24, F11.150, F06.2</th>
</tr>
</thead>
<tbody>
<tr>
<td>19</td>
<td></td>
<td></td>
<td>Includes paranoid state (simple), delusional disorder, paraphrenia (schizophrenia characterized by delusions), shared psychotic disorder (related persons of the same family share the same delusions), other specified paranoid states, and unspecified paranoid state</td>
</tr>
</tbody>
</table>

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<thead>
<tr>
<th></th>
<th>Intellectual Disabilities</th>
<th></th>
<th>F79, F72, F73, F84.9, F71</th>
</tr>
</thead>
</table>
|20 |                           |     | conduct NEC, unspecified disturbance of conduct  
  ● Disorders mainly involving aggressive and destructive behavior and disorders involving delinquency  
  ● It should be used for abnormal behavior, in individuals of any age, which gives rise to social disapproval but which is not a part of any other psychiatric condition  
  ● To be included, the behavior must be abnormal in its context |
Appendix 2.

Incomplete transcripts of psychiatric consultations with patient KW.

Visit 1

**Psychiatrist:** Tell me, lately, how are you feeling with your medications?
**KW:** Good.

**Psychiatrist:** Any side effects?
**KW:** [No.]

**Psychiatrist:** How is your mood? Depression, suicidal thoughts?
**KW:** [No, none.]

**Psychiatrist:** Any voices?
**KW:** [Not really.]  

**Psychiatrist:** You still like to listen to music?
**KW:** [Yeah.] It makes me feel good.

**Psychiatrist:** I will check your memory now. Where are we now?
**KW:** [New York.]

**Psychiatrist:** What month? What city?
**KW:** [Uh, July. Manhattan.]

**Psychiatrist:** How do you usually spend your time during the day?
**KW:** [Sitting here, listening to music.]

**Psychiatrist:** Now I’m going to check your arms, to see if you have any tremors.

...  

**Psychiatrist:** Now I will move your arms.

...  

**Psychiatrist:** Now stick your tongue out.

...  

**Psychiatrist:** Do you know who I am?
**KW:** Linda? Beautiful? Matilda?

**Psychiatrist:** I am the psychiatrist!
**KW:** Oooohhhh!

*We said goodbye and left.*
Visit 2 - 18 days later

**Psychiatrist:** I thought you said you were feeling suicidal.

**KW:** [*off-topic ramblings*]

...

**Psychiatrist:** Tell me exactly what happened.

**KW:** [*non-linear response*]

**Psychiatrist:** What happened with the knife?

**KW:** Because I didn’t get a cig in the morning. So I wanted to die. I took the knife and took it and told her I didn’t get a cigarette.

**Psychiatrist:** Do you still have these thoughts in your mind?

**KW:** No.

**Psychiatrist:** How about your depression?

**KW:** So many people here want to fight me because they’re jealous.

...

**Psychiatrist:** [Why did you refuse your medications yesterday?]

**KW:** I decided not to take it because I don’t wanna stay here because so many people want to kill me and I don’t want to be the last person on earth to die.

**KW:** I took the pills though, is that what you want to hear?

**Psychiatrist:** Are you afraid of other people?

**KW:** Of course I am.

**Psychiatrist:** Why? [Why do you think people want to kill you?]

**KW:** [spoke about a story with some woman] … Well why do you think hell exists? We are in hell. I want to go to heaven. … When I take the medication, it adds more time. … I’ll never get out of here, dead or alive… I talk to God. God talks to the social worker. You talk to God, too.

...

**Psychiatrist:** Do you remember them? [*points to Sophie and me*]

**KW:** [*Thinks Sophie McAllister is Sophie Park*]

...

*We prepare to leave.*

...
Visit 3 - 3 days later

PsYchiatrist: How was your weekend here?
KW: My weekend is always nice.
PsYchiatrist: Did you listen to music?
KW: Yes
PsYchiatrist: What week is it?
KW: 10th of August
PsYchiatrist: How old are you?
KW: 8.
PsYchiatrist: Still child?
KW: Mhm
PsYchiatrist: Okay. What day is it today?
KW: Monday
PsYchiatrist: What month?
KW: August
PsYchiatrist: What day?
KW: 8th
PsYchiatrist: How old are you?
KW: 56
PsYchiatrist: But you said you are 8 years old?
KW: My body is like an 8 year old.
PsYchiatrist: So you are afraid of other people killing you?
KW: Yeah, yeah. … Then someone over there shooting bullets at me. Or with a baseball bat.
PsYchiatrist: Why are you thinking about this?
…
PsYchiatrist: Tell me: you said you are afraid of people here.
KW: Yeah. People here are cops. I'm a detective. Colombo.
PsYchiatrist: Don’t be afraid of people here.
KW: I'm gonna try not to. … Nah there's just one particular guy. What does he want from me? He want steak every day?
…
PsYchiatrist: Okay, Mr. KW. So don't do anything wrong to yourself, to others.
Visit 4 - 2 days later

... 

**Psychiatrist:** How about your medications?  
**KW:** Very good. I miss my wife.  
**Psychiatrist:** I see, you miss your wife. Are you feeling depressed?  
**KW:** Yeah. No no no.  
**Psychiatrist:** Suicidal thoughts?  
**KW:** No.

...  

**KW:** I swear to god I'm not going to hurt myself no more. ... I felt like a rib coming out of me today. Like a wishbone came out of me. Somebody took it.

...