

Spring 6-16-2022

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Recommended Citation

Harbury, Britta, "Neuroscience-Informed Self-Advocacy for Individuals with Psychiatric Disorders" (2022).
University Honors Theses. Paper 1211.
<https://doi.org/10.15760/honors.1196>

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Neuroscience-Informed Self-Advocacy for Individuals with Psychiatric Disorders

by

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An undergraduate honors thesis submitted in partial fulfillment of the

requirements for the degree of

Bachelor of Science

in

University Honors

and

Psychology

Thesis Adviser

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2022

Abstract

Self-advocacy is an effective way to foster improved quality of care for people with psychiatric illnesses. By understanding their conditions and needs they are better able to collaborate with their clinicians and form effective treatment plans. Introducing basic neuroscience to individuals with mental illnesses equips them to navigate the American mental healthcare system, which relies on neuroscience to create diagnoses and medications. This thesis aims to create neuroscience-informed mental health resources so that individuals with psychiatric disorders can access information that may help them better advocate for themselves in the future.

Mental Healthcare in the United States

The United States mental healthcare system is predicated on an epidemiological model of psychiatric illness. This approach to mental health gained prominence during and after World War II as an alternative to psychoanalysis. Psychoanalysis believes that each individual comes with their own individual psychopathologies that cannot be separated into discrete diagnoses. Although psychoanalysis can be useful in an individual therapeutic context, its individually-tailored approach was woefully inadequate to support the influx of traumatized veterans returning from World War II (Murphy & Leighton, 2009). The epidemiological model of mental health views psychiatric illnesses as discrete, diagnosable entities. These illnesses could then be treated via well-established therapies, resulting in quality-of-life improvements for the client. The Diagnostic and Statistical Manual of Mental Disorders, the DSM-5, is the current criteria for all diagnosable mental disorders in the United States (Horwitz & Grob, 2011).

There are definite strengths to the epidemiological model of mental health. Discrete diagnostic labels allows for the collection of data, which can inform therapeutic advancements

and public policy (Kelly, 2017). Clear diagnoses with required symptoms can standardize diagnosis, minimizing clinician biases. Public screening programs can also help identify individuals who may benefit from psychiatric treatment (Horwitz & Grob, 2011).

Unfortunately, there are also some massive problems with the epidemiological model of mental health, especially with its validity. Accurate diagnoses require that an appropriate diagnosis exists and that diagnoses are distinguishable from each other (Horwitz & Grob, 2011). For example, the DSM-5 contains an entire section for potential disorders it does not yet diagnose and there is substantial overlap between criteria for schizophrenia, schizoaffective disorder, and bipolar disorder with psychotic features (American Psychiatric Association, 2013). Although acknowledgement of future areas of research is a good thing, the presence of an entire nebulous section indicates that the DSM-5 may not contain all the diagnoses required to support clients. Emerging neuroscience and genetics also suggests that psychiatric diagnoses are far more nuanced than once thought. The DISC1 gene is a connecting factor between individuals with schizophrenia, schizoaffective disorder, bipolar disorder, and major depressive disorder. The common involvement of this gene implies that all of these disorders may be caused by errors in the same proteins (Porteous et al, 2011). These findings suggest that mental illnesses may be spectrum disorders, similar to autism - another disorder also associated with the DISC1 gene.

Regardless of the issues in the epidemiological model, it is what the United States healthcare system utilizes and what mental healthcare clients must learn to navigate. Juggling medications and diagnoses can be difficult, especially in a landscape that is shifting as rapidly as contemporary psychopathology.

Self-Advocacy

Cassidy Wilson was a neuroscience student at the University of Chicago. In June 2021 she was committed to a psychiatric hospital against her will and later chose to share her story. After calling a student crisis line for emotional support she was surprised by campus police officers who proceeded to handcuff her and took her to a hospital. In spite of her vigorous protests, she was isolated, threatened with restraints, and placed on suicide watch. She was pressured into consenting to the hospitalization process and given medication without her approval (Wilson, 2021).

Cassidy's ordeal reflects an abundance of similar stories of abuse. These abuses come from a system where mental health service-users are often cut off from their supports, which forces the person undergoing a mental health crisis into the impossible position where they must advocate for themselves (Wilson, 2021). Self-advocacy is a critical facet to improving the mental healthcare system. The best way to protect oneself from abuse in an inpatient hospital is to avoid hospitalization entirely. By teaching people to self-advocate, they become better equipped to self-regulate and to actively participate in their own care.

Self-advocacy has many aspects. To self-advocate for oneself one first must understand themselves and their condition. In a mental health context this means both understanding their diagnoses and their needs in order to manage their diagnoses. They must also know their rights, have connections with others in the mental illness community, and be able to take leadership roles in this community (Test et al., 2005). In short, all mental healthcare service-users should understand what they have and how to deal with it, and this information should partially come from fellow people with mental illness.

Corinna West is one such advocate. She has been diagnosed with schizophrenia and now works as a peer mental health specialist and activist. In her experience, peer support is critical for

people with mental illness. There is a fundamental difference between speaking with a medical professional who understands the illness through academic knowledge and a person who actively lives with the issue. A neurotypical medical professional simply cannot understand the nuances of a disorder (West, 2005). West specifically targets medical literacy in her advocacy work. In our epidemiologically-informed mental healthcare system a spectrum of disorders are grouped under one diagnosis. The experience of a person with mental illness is unique to them.

Psychiatric medications work differently for different people. Some people do not respond well to the first, second, or third medication they are placed on. Psychiatric medications are infamous for their unpleasant side effects; it is no wonder that someone who has only experienced suffering from pills may be hesitant to take their medications. These individuals can then be seen as uncooperative and treated as hostile. West's solution to this problem is simple; teach the mental healthcare service-user about how their medications work, listen to their experiences whilst taking these medications, and allow them to stop taking a medication if it is not working (West, 2009).

A 2011 research study of individuals in the HIV positive community utilized aspects of West's philosophy to great effect. The study created treatment advocacy programs for their HIV positive clients where they were encouraged to ask questions about their care. These programs were positively correlated with medication adherence, improved support for comorbid conditions, and empowerment to navigate the healthcare system (Mutchler et al., 2011). If increased education and support led to improvements within the HIV positive community, then a similar approach should be attempted with knowledge of mental illness.

The cultural understanding of neuroscience frequently does not align with reality. Neuroscience in media often revolves around mad scientists manipulating the brain, often with

nefarious goals. For example, brains being manipulated to create superhuman beings is a common trope (Alftberg & Bengtsen, 2018). Although most fictional neuroscience is absurd in reality, it does capture how the human brain is one of the most complicated things known to mankind. The field does not know as many things as it does know. Cutting-edge research frequently reshapes neuroscience as the gaps are slowly filled in. Even though neuroscience is both complex and malleable, however, it is still possible to present these concepts to the public.

NW Noggin is a nonprofit group founded by Jeff Leake and Dr. Bill Griesar. They work to spread community knowledge of neuroscience through a combination of outreach and art. A typical NW Noggin event features engaging in collaborative discussions, crafting pipe cleaner neurons, making block prints of neurons using local plants, and holding real donated human brains (NW Noggin, 2022). Using this interdisciplinary approach NW Noggin is able to describe neuroscience concepts to everyone from preschoolers to high school students to houseless youth to people undergoing substance use disorder treatment. Experiences with NW Noggin form a critical part of this thesis because their outreach strategies made it clear that it was possible to bring neuroscience into mental healthcare service-user communities, so long as the concepts were presented correctly. NW Noggin later became the vector to spread these neuroscience-informed mental health resources.

Methods

The current mental healthcare system is heavily reliant on neuroscience, especially when it comes to psychiatric medication. Viewing mental health as a purely neurochemical phenomenon is a reductive perspective, but a perspective nonetheless sometimes taken by our mental healthcare facilities. If the mental healthcare system relies on a pharmacological view of mental illness and if understanding oneself and one's diagnoses is a critical part of self-

advocacy, it makes sense to present neuropharmacological information to individuals with mental illnesses. This thesis aims to create neuroscience-informed resource pages about various mental illnesses and distribute these resources into the community.

To make these resource pages it was first necessary to locate sources. Due to the public nature of this project, it felt important to utilize only open-source articles, books, and websites. The final resources featured two free digital textbooks, a link to a psychiatric medication guide, an interactive digital brain, and various open-source papers pertaining to specific disorders. The only non-open-source resource used was the DSM-5, which is available at many public libraries.

There were two consistent main sections of the resource pages: 1. what parts of the brain are affected by various mental disorders, and 2. how medications commonly used to treat the disorder affect neurotransmitters in various parts of the brain. Each resource page also featured a brief description of what neurotransmitters are and the function of any neurotransmitters discussed in the medication section. Disorders that inhibit executive function all feature a section explaining what executive functioning is. There is also a section encouraging individuals who recognize symptoms in themselves or a loved one to seek medical attention.

Making the “Parts of the brain that are affected by...” sections required generalizing and simplifying large areas of the brain. Focus was placed on how various parts of the brain were tied to mental disorders, as well as how they were connected to common side effects. For example, when discussing the basal ganglia and the cerebellum motor function was discussed both because bipolar disorder and schizophrenia can have movement-based symptoms and because many medications to treat those disorders often have movement-related side effects.

Summarizing psychiatric drug action was complicated. Selective serotonin reuptake inhibitors, lithium, typical antipsychotics, atypical antipsychotics, barbiturates, benzodiazepines, and antihistamines were all discussed. The section centered around how certain neurotransmitters interacted with the brain. This information was ideally paired with specific affected areas of the brain, combining to form a brief description of how the drug could alleviate certain symptoms and why it may cause certain side effects.

Each individual disorder resource included a summary of the disorder. They each also received personalized sections discussing important facets of the disorder that were not adequately explained in the prior sections.

The anxiety sheet featured symptoms of long-term anxiety and the difference between panic and anxiety attacks. Long-term anxiety was discussed because symptoms such as headaches and digestive problems are often not connected to anxiety disorders in the public consciousness. Panic and anxiety attacks were discussed because the terms are often seen as synonymous, even though they have clear clinical differences.

The bipolar disorder sheet included a discussion of mania and hypomania. This section also included a brief description of mixed episodes. It was important to discuss mania and hypomania because these mood states make up a large part of bipolar disorder. Additionally, hypomania is often less discussed than mania, leading to misconceptions about the symptom. Mixed episodes were critical to include because they are a primary reason for bipolar disorder's lethality.

The major depressive disorder sheet included a longer list of symptoms and a discussion of suicide. The symptom list was important to emphasize how depression can manifest itself in a

plethora of ways, some the polar opposite of each other. Depression looks different from person to person, so it is important to address the variety of potential symptoms. Discussing suicide was important for three reasons. First, it is a subject rife with misinformation and stigma, making nonjudgmental discussion critical. Second, it felt important to directly address any people reading these resource sheets who are living with active suicidal ideation. There is a great deal of hope for people living with mental health disorders that is not conveyed to the people actively living with the disorder. Those living with suicidal ideation often report feelings of hopelessness. They should know that new treatments are being discovered. Finally, discussion of suicide needs to come paired with resources for people who are an immediate danger to themselves. It would be irresponsible to discuss suicide without providing support to people who may be triggered by these discussions.

The psychotic disorders sheet included a discussion of various types of hallucinations. It was important to discuss how hallucinations can affect every sense, not just vision and hearing. Difficulties with discerning a hallucination from reality was also discussed, more for the people who have not undergone psychosis. Understanding the extreme realism of some hallucinations may lead to increased understanding in people who have never experienced psychosis themselves.

The PTSD sheet included an extended list of symptoms and a discussion of dissociation. PTSD, like anxiety and depression, feature symptoms that are often not connected to PTSD by most people. Every case of PTSD is also different and may present in drastically different ways. Dissociation is a common trauma response that can be associated with PTSD. It can be an alarming experience if one does not know what is happening to them. Additionally, witnessing dissociation can be an alarming experience for a bystander if they do not know what is

happening. Any increased public awareness can provide additional support and understanding for a dissociating person from the community.

Once these resources were made, they needed to be spread into the community. This work is now available on NW Noggin's website and was also presented to two communities intertwined with mental healthcare (Harbury, 2022).

TRIO Conference

TRIO consists of various federally-funded programs that aim to assist disadvantaged students in pursuing higher education (U.S. Department of Education, 2022). The design of this thesis was influenced by an outreach experience with Alliance High School, a TRIO-affiliated alternative high school in Portland. A collaborative, vulnerable discussion took place that epitomized how peer-presented neuroscience can empower individuals with psychiatric disorders.

The Oregon branch of TRIO had a statewide conference in April. NW Noggin was invited to host a breakout session, which provided an opportunity to present these aggregated resources. Many of the students TRIO helps are living with psychiatric disorders or are at high risk to develop psychiatric disorders later in life.

This conference highlighted how critical self-advocacy is for people with mental illness. By conveying simple neuroscience-informed diagnosis and medication information several people had begun to connect their symptoms and experiences, as well as knowing that their experiences were often normal for their condition. Some individuals learned about critical aspects to their psychiatric disorder for the first time from the presentation of these neuroscience-informed resources.

The presentation also catalyzed discussions about mental health experiences, both during the breakout room and after it. Presenting neuroscience as an aspect of the conversation allowed people to share their own knowledge and experiences, further facilitating an exchange of knowledge that can only come from self-advocacy. Stories have power. Cultivating an environment where people could openly self-disclose about their experiences allowed for a rich exchange of personal knowledge that is integral to discussions of mental health.

Bridges to Pathways

Bridges to Pathways is a residential substance use disorder rehabilitation program funded by Columbia Community Mental Health. It aims to treat substance use disorders with a holistic, client-centered approach. This philosophy makes Bridges to Pathways especially well-suited to clients with complex cases, including comorbid psychiatric disorders (Columbia Community Mental Health, 2019).

NW Noggin held an outreach event May 19th, 2022. The first half of the event was a group discussion, followed by opportunities to craft pipe cleaner neurons and hold human brains. Much of the discussion understandably revolved around substance use. Once again, individuals living with these conditions had excellent questions and contributed invaluable personal experience. Clients requested more detailed explanations of concepts that had been briefly mentioned in therapy and doctor's appointments. Neuroplasticity and neurogenesis were popular subjects. There were also several questions regarding specific disorders, including Tourette syndrome and Parkinson's disease.

These questions present a consistent theme: the desire for more detailed information about neuroscience topics that directly affected them. Later personal conversations also followed

this theme, with people often self-disclosing their diagnoses. As these discussions progressed, a sense of hope developed. For example, many clients entered the discussion believing that once neurons were destroyed the entire brain section was lost forever. In reality, neuroplasticity and neurogenesis suggest that there are ways for the brain to heal from damage caused by substance use.

Discussion

In a healthcare system that revolves around the concept of discrete, treatable disorders, neuroscience forms the cornerstone of contemporary treatment, especially where drugs are concerned. Frustration over medication side effects was, understandably, a running theme. Psychiatric drug side effects can include nausea, weight gain, weight loss, sexual dysfunction, drowsiness, insomnia, motor or verbal tics, and personality changes; this list is by no means exhaustive (National Institute of Mental Health, 2022). Understanding the basic principles of psychopharmacology allows clients to better navigate this minefield of drug effects.

Neuroscience can be a powerful therapeutic tool, if used properly. Current research about neuroscience is brimming with new ways to treat psychiatric illness. The presence of the DISC1 gene suggests that drugs targeted for DISC1-associated proteins may be able to affect the brain in specific locations, which would theoretically cause fewer side effects (Porteous et al, 2011). The emerging study of neurogenesis, the regrowth of neurons, also has lifechanging implications for individuals with mental illness. Physical exercise and environmental enrichment are correlated to stimulation of neurogenesis, meaning that brain damage caused by a psychiatric illness may be reversible (Schenfeld & Cameron, 2015). These discoveries, amongst many

others, suggest that neuroscience is in the midst of a paradigm shift that will change how psychiatric illness is viewed and treated. There is hope.

Fostering an environment where psychiatric knowledge can be shared between individuals with mental illnesses is a critical way to disseminate this information. Personal experiences add a dimension to these discussions that most clinicians cannot have. Additionally, people may feel safer asking questions and sharing information if they know their audience has lived through similar experiences (West, 2011).

Conclusion

The experiences catalyzed by this thesis align with the literature in the field. Individuals who were presented with knowledge generally felt better equipped to actively collaborate in their care. Misinformation could also be dispelled, which was especially critical when the incorrect knowledge painted psychiatric illnesses as an insurmountable, unrecoverable thing. Sometimes the best way to bring optimism is through the truth.

The American mental healthcare system relies on an epidemiological model, resulting in care that is rooted in neuroscience. Neuroscience is a field that is evolving at an astounding rate, meaning mental healthcare providers can be slow to update their practices accordingly. The clients that these providers serve can suggest new perspectives on their treatment and can request changes to their existing care plans. If people understand why their treatment plan is the way it is, they are more likely to adhere to the program (Mutchler et al, 2011). Additionally, the person taking the medications knows what is happening in their body better than anyone else. Cassidy's traumatic involuntary inpatient hospitalization shows exactly what can happen if a client's needs are not listened to. Instead of receiving care, the hospital retraumatized her and later billed her

for the stay. If any of the police officers, nurses, doctors, or psychologists she encountered had taken her opinions on her care into account, perhaps Cassidy would have been spared some of the trauma the system inflicted onto her (Wilson, 2021).

The unfortunate reality is that some people, like Cassidy, can hold all the right knowledge, say all the right things, and still be abused. Instead, the goal can be shifted to keeping people stable enough that it is harder to force them into inpatient treatment. West's advocacy work illustrates exactly why that approach can work. Peer advocacy allows clients to see that there are ways out of their current predicament and learn how to adapt the shared experience to their life. Being educated on what questions to ask a psychiatrist can be life or death. People who have already had to advocate for themselves are best equipped to pass that information on (West, 2009).

Creating neuroscience-informed accessible resources and presenting them in a conversational format where individuals can share their personal experiences blends these two worlds. Everywhere these resources were presented saw passionate, empathetic discussions that promoted peer advocacy. Above all else, these discussions fostered hope as individuals gained more power to control their own care.

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