REIMAGINING PSYCHOSIS: THE MEANING-MAKING OF LIVED PSYCHOTIC EXPERIENCES

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For Ahmad. You are an immense source of light in my life, shining brighter than even the sun.

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Abstract

Tracing the lines between intersectional, marginalized Mad bodies, I illustrate a picture of psychotic Madness across borders, boundaries, and times, as well as the struggles of living this kind of existence while butting heads with Western psychiatry. Using feminist autotheory as a methodology, I weave my experiences with psychosis into a greater tapestry of what it means to be unwell, positing my own theories about how psychosis operates. Within my theorizing, I explore how 'symptoms' of psychotic 'illness' may be reconceptualized as coping mechanisms for survival in the midst of traumas and stressors. For example, some individuals develop 'delusions,' also known in less-clinical settings as strong beliefs, to contextualize their sensory-perceptual intrusions, such as hearing voices. Furthermore, I explore three case studies of different experiences with psychosis from mothers with postpartum psychosis to migrants and refugees with schizophrenia, questioning the nature of how these 'illnesses' are constructed, if they are even 'illnesses' at all. I dream of more holistic ways to think about and work with psychotic individuals, privileging their opinions and unravelling their stories of injustice and misrepresentation. Finally, I put forth alternatives to the biomedical treatments found in Western psychiatry, focussing instead on social support, such as peer support networks or affirming and validating one's reality.

Keywords: Psychosis, coping mechanisms, autotheory

Introduction

~ "Citation, placed next to memory, becomes a way of making one's life intelligible" (Fournier, 2021, p.144).

To imagine writing, or doing anything, without infusing pieces of oneself into the process seems nearly impossible. Autotheory, which does just that, is a relatively new practice popping up in feminist writings in the early 2010s (Fournier, 2021). Autotheory challenges dominant perspectives that academic or scientific writing should be somehow 'objective,' devoid of personal voice (Fournier, 2021). Throughout this paper, I infuse my own voice and opinions into the topic at hand, which concerns how Western psychiatry shifts and shapes the lives of a select group of Mad people. Using my own knowledge, and the knowledge of various physicians, psychiatrists, activists, sociologists, and others, I trace the lines of similar veins across many marginalized, intersectional, and Mad bodies, sharing what we know and process through embodiment. I imagine different ways of interacting with or speaking about people who are severely unwell and alternative, self-determined forms of care for them. Starting with my own story, I am critical of the encounters I have had with Western psychiatrists, and I dream carefully of better ways to hold someone else's life in your hands.

The Admitting

I sat dreamily in my chair, swaying. The lilting feeling of swishing back and forth feels nice as the cool air creeps up my skin in the dingy hospital admitting room. If only someone would tell me how I had gotten to be sitting. "Do you know why you're here?" The admitting nurse suddenly asks me. She eyes me carefully. Does she know something I do not? "My Dad and sister took me here because I haven't eaten in 5 or 6 days." Satisfied I know the correct reason for being in the hospital, I am silenced again. My father has his own report for her and insists that I am threatening our family and demanding that my mother leave our home. Funnily enough, I do not remember the car ride getting here, nor anything in his statements. Years later, looking over my medical reports, I will note that the admitting nurse wrote that I was too ‘sedated’ to be of much help during my intake. My father and the nurse begin acting as if I am not there, but lovely waves are crashing in my ears, and I let them take me to sleep.

When I first remember waking up in the hospital, I had been sleeping for about 3 days straight with little time awake. My body was sore. My thoughts were muddled and wispy-like, dissipating when I reached for them. I had no recollection of coming to the hospital, although many memories have come gradually back with time. Something was clearly afoot, and I was eager to play detective. At certain points in the weeks leading up to the hospital, I experienced flashbacks to instances of childhood abuse that I had forgotten about—confusing and unsettling memories that made me squirm. In my mind, I began churning over my symptoms—flashbacks, nightmares, gaps in memory—it all seemed to match up with what my cognitive psychology textbooks would describe as PTSD, but why was I grasping for my own mind so much? Why did it seem to be fading in and out?

Psychosis

Psychosis is a contentious and stigmatized phenomenon, typically described as an ‘illness.’ I would first come to know about psychosis in August of 2021 during a three-week hospital stay, followed a month later by a two-week hospital stay in October of 2021. One of the most salient characteristics of psychosis is that psychotic individuals tend to deny having an ‘illness,’ and I was no exception (Roe et al., 2008). In fact, it would take about six months to gather a solid sort of understanding that I was quite unwell. It was the summer, after all. My backyard was bursting with blossoming flower gardens, and my winter blues had long melted.

Who could develop psychosis under the bright, shining sun? If I think back hard enough, I am not even sure I knew what psychosis was when I got diagnosed with it or if anyone sat and talked with me long enough to give me a chance at understanding it.

According to the Ministry of Health and Long-Term Care in Ontario, Canada, only about 0.0001% of people will go through psychosis, so it is not necessarily a common dilemma, yet psychosis is frequently described using terms like ‘debilitating’ (2011). As the Ministry further explains, some of the experiences that psychotic individuals go through include “delusions, hallucinations, disorganized thinking, and/or bizarre behaviour,” yet, as I will later explain, these terms are highly clinical and not necessarily accepted by psychotic individuals themselves (2011, p. 6). Psychotic individuals are not often discussed in Western media or in public, especially in a neutral or positive light; instead, their voices are often hushed away in institutional settings. When they are portrayed, it is usually for the benefit of others; for example, in the instances of horror novels or films, psychotic individuals become dazzling and profitable antagonists (Wahl, 2006). In reality, psychotic individuals are more likely to be homeless, incarcerated, and/or unemployed than the general population—not so dazzling after all.

Treatment for psychosis across the Western world, on which this paper will focus, often includes antipsychotic medication, sometimes in conjunction with psychosocial support, such as psychotherapy using the CBT model (Warner et al., 2021). Furthermore, there are Early Intervention Psychosis (EPI) programs that aim to treat psychosis within youth before it can create long-term consequences; in particular, Canada has been at the helm of EPI development alongside several other countries, such as the UK and Australia (Iyer et al., 2015). On the flip side of the same settings, Canada and the United States, although they do not comprise all of the Western world, have been the sites of countless instances of horrific abuses toward psychiatric consumer survivors, also known as psychiatric ex-patients, which will be covered in several case studies later in this paper. Concurrently, Canada has also been at the forefront of the contemporary Mad Movement, which seeks to elevate the voices of psychiatric consumer survivors and will be further discussed in the next section.

The Contemporary Mad Movement

Terminology

‘Mad’ as in crazy, insane, unwell, psychotic, manic, ruminative, paranoid, or otherwise known as ‘mentally ill.’ The contemporary Mad Movement can be thought of as “…a living, and constantly evolving, field of political engagement and struggle for social justice,” which sets its sights on the freedom for all from psychiatry and its harms—institutionalization, over-pathologizing, and overmedicating (Menzies et al., 2013, p. 11). Within the Mad Movement, Mad Studies is the critical academic approach to understanding and unwrapping mental distress (Beresford et al., 2022). There are subsets of Mad Studies, such as Critical Autism Studies, and I would suggest that my paper would fall under Critical Psychotic Studies—a discipline that sadly does not exist yet. Furthermore, Mad Studies has emerged from, and sometimes beside, Disability Studies, which is an interdisciplinary academic approach to exploring the voices and experiences of disabled people, centring their forms of knowledge and asking important questions about how greater society views and treats them (Beresford et al., 2022). Acknowledging lived experience is at the heart of both these academic disciplines, and as this paper takes its influences from both, so too will acknowledging lived experience be the heart of this paper (Beresford et al., 2022).

In my experience, I have had Madness drip from my fingers like liquid gold, which means I am whom the contemporary Mad Movement and the discipline of Mad Studies might call a ‘psychiatric consumer survivor’ or a ‘psychiatric ex-patient’—someone who has been in the psychiatric system (Menzies et al., 2013, p. 10-14). We might call someone currently in the system a ‘service user.’ These terms provide more agency than the word ‘patient,’ who might seem like a passive recipient of treatments and medications. The common goal of consumer survivors and service users who join under the umbrella of the Mad Movement is to fight back against ‘sanism’—the discrimination that those deemed mentally ‘ill’—or crazy, paranoid, insane, manic—face.

Notably, I will refer to certain terms, such as ‘mental illness,’ in single quotations to represent that this is a highly clinical representation of mental variation—one with which I do not necessarily agree. Many psychiatric consumer survivors do not consider themselves to be ‘ill’ but rather different or even traumatized. What it means to pathologize someone’s natural despair or response to trauma will be discussed in the following sections. Some people do consider themselves to be ‘ill,’ however, and find that psychiatric diagnoses are helpful for navigating their despair, and this is acceptable for them. Whatever the case, the goal of ‘treating’ a ‘mental illness’ should be to remedy the cause of a person’s pain or despair, and as we will later find, this is not always what happens in psychiatry.

A Brief History – 1960s to Present

While the contemporary Mad Movement sprang up roughly sixty years ago, Madness has existed much longer than that—the Bible, for example, speaks of Madness, “The Lord will smite you with madness and with blindness and with bewilderment of heart…” (*New American Standard Bible 1995*, 1995, Deuteronomy. 28:28). Notably, and rather sadly, there are limited direct accounts of Madness from before the mid-19th century. The oldest is likeliest from Margery Kempe in 1436 (Reaume, 2017). Yet, even the most influential Mad writers are not necessarily well-known; their accounts are not seen as ‘evidence’ of what it is like to be mentally ‘ill’ (Reaume, 2017). What will emerge then, in these pages, are the stories of people like me. The Psychotics. Schizophrenics. The Bipolar. The Traumatized. The voices that must find their way, bubbling up through the cracks of the very social systems that aim to medicate and institutionalize and dismiss and hide them. This is how they emerged, once again, several decades ago.

The contemporary Mad Movement came to fruition in the 1960s and 1970s during a time when many other radical movements were springing forth, such as gay and trans liberation (Menzies et al., 2013). At this time, relations between psychiatry and society, the individual and the state, were radically shifting, especially as the mental health industry was expanding and flooding the marketplace with abundant prescriptions like Prozac (Menzies et al., 2013). With the publishing of the psychiatric diagnostic manual, the DSM, in 1952, brazen psychiatrists found themselves ready to diagnose any and all proponents of modern life, even and maybe especially our deepest thoughts (Menzies et al., 2013). Reactively, the Mad Movement surged once again, rekindling the flames once set by asylum survivors in the early 1900s, with consumer survivors finding new strength in numbers (Menzies et al., 2013). Inevitably, as the authors of “Introducing Mad Studies” write, “…the psychopolitics of [the 1960s-1970s] were volatile and complex” (Menzies et al., 2013, p. 4).

Unfortunately, the Mad activism of the 1960s and 1970s, the golden age of anti-psychiatry, did not come without powerful backlash (Menzies et al., 2013). Medical professionals and academics alike became entrenched in relationships with Big Pharma to form “…the most nefarious influence on the lives of millions of people categorized as “mentally ill” the world has ever seen…” (Menzies et al., 2013, p. 6). Other concerning developments arose in the 1980s and 1990s, such as the recurrent rise of electroshock therapy or myths about deinstitutionalization causing social inequities (Menzies et al., 2013). Thus began a legacy of overmedicating and over-pathologizing "...and all from a Western, American-centric, culturally narrowminded perspective" (Menzies et al., 2013, p. 6). At the same time, into the 21st century, "…critical [Mad] scholarship and activism have flourished around the world as never before[,]" with global epicentres in the Americas and Europe, which are slowly expanding into other regions, such as Asia (Menzies et al., 2013, p. 8).

Theorizing Psychosis

While psychiatric literature has often posited mental illness as an "…objective material biological problem…" that is "…separate from culture and society…" – this is not necessarily the whole story (Morrow & Malcoe, 2019, p. 6). What is often missing from the dialogue among psychiatric experts are more-rounded perspectives that include the "…social, political, cultural, and economic production of mental health problems and solutions" (Morrow & Malcoe, 2019, p. 6). Not to mention, there is often the absence of patient perspectives on their own care; for example, under involuntary care, I often tried to explain the physical symptoms of anxiety I was experiencing, yet I was frequently told, rather dismissively, that this was simply psychosis. Furthermore, it was reported in my hospital records on multiple occasions that I was "resistant to reality orientation." Yet, as any experience of reality is subjective, did anyone try to orient themselves to my reality? Or did anyone try to break down the complex psychological mechanisms driving my psychotic experiences? The answer is disappointing.

Importantly, "The relationship between trauma and psychosis is now well established (Hardy, 2017). In *Psychosis as Personal Crisis*, there are two influences on psychosis: "1. The influence of earlier traumatic experiences, creating a vulnerability to psychosis 2. The actual stress or personally significant events that cluster before the onset or relapse" (Romme, 2013b, p. 87-88). In another light, as one study frames it, "… the triggering of a biopsychosocial vulnerability gives rise to sensory-perceptual intrusions…" (Hardy, 2017, p. 3). Unfortunately, illustrating this causality is not easy, especially as "…research is in its infancy" (Hardy, 2017, p. 2). Although research on this topic is sparse, having experienced psychosis leads me to theorize, and even dream, about it.

Some authors theorize that maladaptive behaviour, such as emotional dysregulation, contributes to maintaining psychosis (Alba-Ferrara et al., 2012). In fact, maladapted emotional regulation can be linked to how severely hallucinations are experienced (Alba-Ferrara et al., 2012). It is my suggestion, then, that maladaptive, or perhaps a better term is survivalist, coping mechanisms lead to what we know as 'psychosis.' Psychosis may be conceptualized as a single, fluid illness that is actually a series of complex attempts at sense-making, among other strategies, to cope with disturbances in one's reality, such as hearing voices. More succinctly, I propose that Madness, or more specifically psychosis, is the body-mind's reaction to untenable living conditions with seemingly no way out as a complex set of maladaptive, or survivalist, coping mechanisms (Wirth-Cauchon, 2001). It is important to note that these coping mechanisms are likely to be seen as maladaptive from the perspective of a clinician who is trying to get rid of them, but for a psychotic person who is using them, they are a means of survival. Therefore, I will refer to the same coping mechanisms as 'maladaptive' and 'survivalist' to showcase both the clinical and 'patient' perspectives. Additionally, I believe that clinicians often try to target individual 'symptoms' or coping mechanisms rather than trying to eliminate a psychotic individual's underlying distress, which causes the coping mechanisms.

In theorizing about psychosis, I take influence from psychological, psychiatric, feminist, philosophical, sociological, and activist sources, particularly Civil Rights-era activism, as well as the ideas of psychotic individuals with lived experience—creating a broad tapestry of how Madness functions. For example, Janet Wirth-Cauchon, Associate Professor Emeritus of Culture and Society at Drake University, writes, "What feminist analyses offer… is a way to understand…madness as an intelligible response to unliveable conditions in which other modes of response are blocked off" (Wirth-Cauchon, 2001, p. 185). In a similar vein, the concept of schizophrenia, specifically, as being a means of survival, comes from the work of two Black psychiatrists, Grier and Cobbs, as well as other Civil Rights-era activists and a small but vocal group of White mental health care professionals, like Theodore Lidz, in the United States (Metzl, 2011, p. 124). As the Frederick B. Rentschler II Professor of Sociology and Psychiatry at Vanderbilt University, Johnathon Metzl, writes, "For King, Grier and Cobbs, Jones, and others, schizophrenia was more than a mental illness; it was also a critique of white society, and an identity forged through time and experience and then worn as a mark not of stigma, but of strength and survival" (Metzl, 2011, p. 127). This connection between schizophrenia and Black male identities will be further explored as a case study, found under the section of this paper entitled '*Protest Psychosis – 1960s & 1970s*'.

Another theoretical influence comes from an associate dean at the USC Gould School of Law, Elyn Saks, who is herself schizophrenic and specializes in mental health law, and mentions in her memoir that "It was [Klein's theory] that psychotic individuals are filled with (even driven by) great anxiety, and that the way to provide relief is to focus directly on the deepest sources of that anxiety" (Saks, 2020, p. 90). Furthermore, Saks eloquently describes the anxiety-inducing nature of psychosis, "Once, there'd been a time in my life when thoughts were something to be welcomed, and pored over, like pages in a favourite book…But now thoughts crashed into my mind like a fusillade of rocks…fierce, angry, jagged around the edges and uncontrollable. I could not bear them, I did not know how to defend myself against them…" (Saks, 2020, p. 83). True to my experience, my anxiety while psychotic hit unprecedented levels, but my psychiatrists were more interested in how legible I sounded to them. Subsequently, what psychotic individuals do when they cannot bear their thoughts and/or voices will be discussed in the next section, and my own experiences of psychotic turmoil will be covered in the section following that one.

Another influence for my theorizing is Kate Millett, an American feminist writer who wrote about her experiences with bipolar disorder and psychosis in *The Loony Bin Trip*. In it, she writes, "But what if there were something on the other side of crazy, what if across that line there was a certain understanding, a special knowledge?" (Millett, 2000, p. 85). In this way, psychosis can be seen as a personalized, embodied knowledge that informs the individual of potential harm, vulnerabilities, or triggers. As one study explains, "Voice hearing is…decipherable and intimately entwined to a person's life story" (Dillon & Longden, 2013, p. 129). Next, I will delve into how the 'symptoms' of psychosis become entwined with an individual's life experiences and how these 'symptoms' are actually coping mechanisms in disguise.

Coping Mechanisms of Psychosis

- Speaking very little
- Flat affect, otherwise known as emotional blunting
- Denial of illness
- Strong beliefs or 'delusions'
- Thought insertion -> "These are not my thoughts"
- Thought broadcasting -> "Others can hear my thoughts"

- Thought withdrawal-> “Someone has stolen my thoughts”
- Hearing voices, otherwise known as audio hallucinations

(Cooke et al., 2005; Bell et al., 2020; López-Silva et al., 2022; Johnstone, 2013)

In this section, I will comment on several ‘symptoms’ of psychosis and suggest how they actually serve as survivalist coping mechanisms for a psychotic individual. Furthermore, it is important to note that “Once [patients] receive a psychiatric diagnosis everything they do can be potentially interpreted as a symptom…” (Ussher, 2011, p. 74). This over-pathologizing is not necessarily patient-centred care as it focuses on hyper-analyzing patient behaviour instead of listening to the patient’s sources of distress, which should be the true target of concern. For this reason, I chose to analyze ‘symptoms,’ or rather survivalist coping mechanisms, as I call them, of psychosis that caused me genuine distress.

Flat Affect and Speaking Very Little

In no particular order, the first ‘symptoms’ I will analyze are flat affect and speaking very little. “Interpersonal behavioral studies…have shown that schizophrenia is associated with reduced facial expression…diminished expressiveness…and difficulties in everyday social experiences…” (Fahim et al., 2005, p. 2). Furthermore, an fMRI study posits that this lack of emotional expressiveness may be due to a malfunction of the amygdala (Fahim et al., 2005). Notably, the amygdala is involved in emotional processes; more specifically, it is involved in functions of regulating anxiety and aggression, as well as emotional memory and social cognition (Rajmohan & Mohandas, 2007). Of course, what is lost in a solely biomedical perspective is how a psychotic individual’s experiences play a significant part in their ability to regular emotions like fear, which I will clarify next.

Imagine that two people are talking to you at once. Perhaps, you are a cashier on the phone, and you are also ringing out a customer at the same time, and you have no choice but to help both customers at once due to a problem of short staffing. The customer in the store in front of you is smiling and happily babbling away to you about the weather. However, the customer on the phone is irate about an incorrect charge made on their credit card. Your heart begins to race as you try to manage both tasks at once. As the happy customer speaks, you nod your head at what seems like appropriate intervals. Meanwhile, you are focussing intensely on what the irate customer is saying, as you are naturally drawn to the more intense stimuli—the stimulus that is most likely to turn around and bite you in the butt, so to speak. The happy customer finishes their transaction and leaves, rather disappointed that the cashier seemed preoccupied, only nodding and barely speaking back to them. To the happy customer, it might seem like the cashier did not really care; perhaps, in more clinical terms, the cashier's affect seemed 'flat' or unemotional. Luckily for us, in this story, we have a broader picture of what happened.

Would it not make sense that the cashier might have found it difficult to smile at the person in front of them while someone else was yelling in their ear? In this way, speaking very little or flatly becomes an adaptive response because it is a neutral presentation, while the psychotic person may be experiencing deeper inner turmoil that they are not presenting. Yet, in clinical settings, speaking very little or flatly is attributed to an inability to regulate or recognize appropriate emotions. Given my cashier analogy, this may now seem like a one-sided, ultimately untrue, view of a psychotic individual's presentation. If psychotic individuals choose to hide the anxiety-inducing or hair-raising nature of what they are experiencing, they *are* regulating emotions like fear—by masking them in situations where they would not make sense to others. Then, on top of this masking, expecting a psychotic individual also to match their expressions to others is no different from expecting an autistic individual to express emotions that they do not feel. It is not that they cannot do it, but rather that it takes unnatural effort. And the question remains, do we want to target the underlying distress that a psychotic individual faces, or is our main concern that they present the same way as everyone else? If the answer is the latter, then we are not really 'treating an illness' so much as we are forcing someone in conflict to 'adapt' to a world that does not respect them.

Denial of Illness

As one review article explains, "It has long been recognized that many individuals with psychosis disagree with their clinicians, friends and families about whether they have a mental illness, whether their unusual experiences and behaviours are abnormal, and whether they are in need of clinical treatment" (Cooke et al., 2005, p. 4). To analyze the patient's perspective of this denial, perhaps we should also look at how patients view their psychosis—not as an illness but rather as a series of experiences or phenomena. In one particularly salient book, *Psychosis as Personal Crisis*, psychosis is described as a personal crisis or series of personal crises (Romme, 2013b). In this way, responses to disturbances in a psychotic individual's reality are attempts at managing them through coping strategies or adaptative behaviour. Clinicians would have patients admit that they are ill, while patients may feel as though they are merely adapting to their circumstances as best as possible through an accumulation of coping mechanisms that were likely developed through trauma or serious stress, such as paranoia of others. This begs an important question: are psychotic individuals truly ill, or is traumatized a better framing?

Furthermore, clinicians have undue power over their psychotic patients; they can choose to restrain them, inject them with medicine, hold them in-hospital involuntarily, and more. For a psychotic person who is facing inner turmoil, something that seems very unhelpful is another intrusion, especially an authority figure, into their intense, private inner world. So, rejecting this diagnosis may be a rejection of the clinician's perspective and participation in their patient's life. For example, I often participated in my own form of sense-making while psychotic—analyzing my own experiences for what they felt like and advocating for myself to my clinicians that I could have PTSD. Unfortunately, my psychiatrist in-hospital went to my family for my psychiatric family history; my family readily told him I had not experienced trauma, and why not lie if they played a part in any potential trauma? A recurrent theme in this paper is and will continue to be the absence of serious reflection on the patient's perspective. In another example, I often had strong negative beliefs, or delusions, about my mother, and yet she was told she might have to become my substitute decision-maker if needed. I deeply distrusted my parents and clinicians, and given their conversations about me when I was not in the room, I do not consider this distrust a sign of something wrong with me. Rather, it is a reflection of how I was treated; it was an adaptive response on my part to deny the expertise of my clinicians, especially as it protected me from seeing myself as deficient or lacking as my clinicians saw me. In the section following, I will describe these experiences in more detail, and later on, I will make arguments for what I believe are more appropriate responses on the part of clinicians.

Strong Beliefs or Delusions

Strong beliefs, known in more clinical settings as delusions or irrational beliefs, are a core component of psychotic 'disorders,' including schizophrenia. As one study explains, "Delusions are defined as wildly improbable beliefs that are strongly held despite incontrovertible and obvious counterevidence and despite what almost everyone else believes" (Bell et al., 2020, p. 24). Like other symptoms of psychosis, 'delusions' are thought to be caused by an impairment in a particular part of the brain, such as the area of the brain responsible for inferential reasoning (Bell et al., 2020). However, as the study continues, "…healthy and adaptive social processes can form and maintain delusion-like beliefs [because] they are overwhelmingly socially and relationally themed…" (Bell et al., 2020, p. 25). Congruently, in another study, it is explained that delusions are a response to psychotic individuals' "…unsettling experiences, implying that they do not unduly weight these experiences in forming beliefs" (McKay & Mercier, 2023, p. 127). In this way, strong beliefs or delusions are a psychotic individual's form of inferential reasoning, a normal cognitive function, with their sensory-perceptual intrusions, such as voice hearing (McKay & Mercier, 2023).

Ultimately, strong beliefs or delusions are only a maladaptive coping mechanism because they are confusing and unsettling to others who do not understand them, which may lead to stigmatizing or shunning of the psychotic individual. Yet, simultaneously, it is a healthy response to try and make sense of one's environment, relating it to your sense of self or life story. It would be shocking, and possibly a sign of something else being wrong, if a psychotic individual experienced constant sensory-perceptual intrusions, such as seeing 'fictitious' images, and did not react to them at all. In this way, delusions or strong beliefs are a personal, survivalist coping mechanism, allowing psychotic individuals to cope with what they perceive by integrating it into their reality. For example, when I lived with my parents in between my two hospital stays, I thought I overheard them conspiring against me. I eventually worked myself into an anxious state where I thought they were going to kill me. Subsequently, I called the police, who took me to the hospital for a 'relapse of symptoms.' While I have a somewhat repaired relationship with my parents now, at the time, they had taken my phone and laptop away, which were paid for by myself, and were controlling my phone calls and whom I could see. Although I am disappointed by what happened after I called the police—a return to the hospital—my strong beliefs ultimately got me away from people who were inconducive to my recovery, even if those people were my parents, and even if they did not understand they were hurting me.

Thought Insertion, Thought Withdrawal, and Thought Broadcasting

Common, specific types of strong beliefs or delusions are: thought insertion (“These thoughts are not mine”), thought withdrawal (“Someone has stolen my thoughts”), and thought broadcasting (“Other people can hear my thoughts”) (López-Silva et al., 2022). While these thoughts are often distressing to those who experience them, they too can be the result of adapting to graphic and disturbing sensory-perceptual intrusions, such as intrusive, suicidal or homicidal thoughts (López-Silva et al., 2022). As one study explains, “…delusions such as thought insertion, thought withdrawal, and thought broadcasting do not exist in isolation but rather are part of a complex, heterogeneous internal structure that arise as a narrative of meaning given to the anomalous experience” (López-Silva et al., 2022, p. 8).

Furthermore, these strong beliefs are associated with depersonalization, which is the process of feeling unconnected to one’s sense of identity or thought content (López-Silva et al., 2022). Unsurprisingly, depersonalization is a common response to intense stress or trauma, in which one dissociates from the disturbing content of their thoughts and memories (López-Silva et al., 2022). While dissociating can interfere with ‘normal’ functioning, it is a way of finding internal relief from difficult circumstances (López-Silva et al., 2022). Additionally, it may be a way of slowing down the processing of overwhelming, traumatic thoughts; if someone else has ‘implanted’ the thoughts in one’s brain, then they do not have to be readily accepted as part of one’s narrative since they are perceived as belonging to someone else. While these thoughts can be distressing, and eliminating distress should be of utmost importance for clinicians, sometimes these types of thoughts only receive attention because they seem abnormal, not because they pose harm. In my case, these types of thoughts naturally faded away as my distress did after I left the hospital, began living independently, and felt more like myself. It is my opinion, then, as with all these coping mechanisms, that they should only receive clinical attention if a patient requests it.

Hearing Voices

As the psychiatric diagnostic bible, the DSM-5, tells us, hearing voices is a 'characteristic symptom' of schizophrenia and other related disorders (McCarthy-Jones, 2012). As *Psychosis as Personal Crisis* explains, voices can also be considered part of the range of 'normal' human experiences; for example, "Critical, abusive or bullying voices are seen as a sign of unresolved emotional trauma" (Johnstone, 2013, p. 28). Accordingly, "…there is a strong and likely causative relation between traumatic events and [audio-visual hallucinations], and…this relation is non-diagnosis specific, i.e. that irrespective of what psychiatric diagnosis you have (PTSD, schizophrenia, bipolar), your [voice hearing] may be the result of traumatic events" (McCarthy-Jones, 2012, p. 286). As such, I will examine several different perspectives, such as psychological frameworks, on how trauma may affect the development of voice hearing so that I may explain how voice hearing develops as a coping mechanism.

In a neurocognitive light, "…people who have experienced childhood trauma have been found to have a range of structural changes to their brains as compared to non-abused individuals…We hence see that key neural areas involved in producing voice-hearing experiences, such as the anterior cingulate, the STG and the arcuate fasciculus…are impacted by traumatic events" (McCarthy-Jones, 2012, pp. 297-298). This, of course, does not mean that voice hearing individuals are deficient in any way; this perspective simply explains that there is a variation in how their brain works, and that, truly, is all. For example, as someone who experienced emotional manipulation tactics as a child, I often find myself more anxious and paranoid than some of my peers. But, like a flower learning to blossom with little sunlight, this is an adaptation because it enables hypervigilance to potential harm, meaning that my brain is using its differential structure for protection.

In a psychological light, some authors posit that memory is associated with developing voice hearing; for example, "…a [traumatic] memory is vulnerable to being triggered and entering intrusively into consciousness when stimuli associated with the original trauma occur" (McCarthy-Jones, 2012, pp. 299-300). In this way, voice hearing can be similarly seen as a reminder of past trauma—keeping the voice hearer alert to potential new trauma. Another set of authors suggests that dissociation plays an important part in how voice hearing develops in response to trauma "in which one dissociative part of the personality becomes trauma-fixed and aurally impinges upon the normal, everyday functioning part of the personality" (McCarthy-Jones, 2012, p. 299). This trauma-fixed part of the personality may work in the same way as traumatic memories—earmarking trauma within the brain as a protective mechanism. Fool me once; shame on you. Can't fool me twice, though, I'll never forget what you did. Evidently, regardless of the psychological theory or framework, traumas are frequently associated with the development of voice hearing, and as I have suggested, this is not necessarily a nonsensical maladaptation on behalf of the brain. Some memories will never die because of their weight. This trauma-based explanation is also found in patient accounts on the causality of voice hearing, which I will elaborate on next.

In patient-led movements, there is an effort to de-centralize the clinical expertise of psychiatrists as holding more weight or importance than the expertise of voice hearers themselves (McCarthy-Jones, 2012). Voice hearers do not necessarily find biomedical explanations of voice-hearing sufficient and have come up with their own ideas. For example, "…explanations people themselves had for the causes of their voices included natural reactions to stress, loneliness, sorrow, a life crisis, telepathy, ghosts, demons or spiritual guides" (McCarthy-Jones, 2012, p. 320). As voice hearers are the ones who have to live or cope with their voices, their ideas about them should take priority, although stigmatization, among other concerns, often prevents this from occurring. For example, I have come to believe that the often negative and frightening voices I heard while psychotic—the perceived voices of my family members and nurses—were warning signs in disguise, leading me to believe that the people in charge of my healthcare or other elements of my life were not out to protect me after all. As such, I chose not to put faith in my clinicians and worked to come up with my own explanations for what I was experiencing. In the next section, I will show through personal examples just how the coping mechanisms of psychosis that I developed, such as voice hearing or strong beliefs, worked to protect me, even as they struck nerves. In the sections following my experiences, I will go through a series of case studies of different groups of psychotic individuals, examining how and why their potential coping mechanisms arose, spanning different time periods, cultural groups, and circumstances.

The Records

In this section, I will delineate a potential misjudgment in my care using my hospital records, which I believe resulted from hospital staff not taking my strong beliefs, also known as delusions, during my period of psychosis seriously. Saliently, I will highlight the absence of patient-centred, trauma-informed care in the context of an inpatient hospital psychiatric ward located in Windsor, Ontario, Canada.

My Mother

As evidenced in my medical records on several occasions, I had multiple strong beliefs, also known as delusions, regarding my mother. My psychotic self painted a clear picture of how I viewed her, for example:

"*The patient [Madison] was seen on the unit in an interview room. The conversation remains largely the same with Madison. She continues to endorse paranoid delusions in regards to her mother…She paints a picture of her mother to be abusive, inappropriate and highly critical*" (Psychiatry Progress Note; September 8th, 2021, 14:09).

In another excerpt from my hospital records, I am quite clear again about how I feel about my mother and her behaviour:

"…[Madison's father] wanted to know if Madison contacted the police, Madison confirmed this stating that she wanted to get a restraining order…against her mother…Madison feels that her mother is controlling and that her mother wants to be in control of her medications. She thinks that her mother is too involved in her affairs. She said that her mother has been relentless" (Psychiatrist Progress Note; September 9th, 2021, 17:12).

Evidently, even though my hospital care team considered me to be quite ill, I was extremely consistent in my dialogue surrounding my mother, and I was subsequently labelled as 'delusional.' Yet, as the following excerpts will show, I was not the only person having issues with my mother, nor was I necessarily wrong about my suspicions that she wanted to interfere in my mental health care. For example:

"*I [psychiatrist] was present during a phone conversation that…social work…was having with Madison's parents. Madison's mother was extremely condescending, patronizing and somewhat hostile during the conversation*" (Progress Notes; September 8th, 2021, 14:09).

In this next excerpt, it is admitted that my mother is trying to change my medications, which I sensed but was not told:

"*…The social worker did report that [Madison's] mother has been calling incessantly, demanding changes to the patient's medications…*" (Psychiatrist Progress Note; September 9th 2021, 17:12).

At the end of my hospital stay, my inpatient psychiatrist admits that the hospital staff have finally concluded that I do not have a good relationship with my mother:

"*It also emerged that there were significant interpersonal issues at home mainly between the patient [Madison] and her mother***"** (Psychiatrist Discharge Note; September 15th 2021, 19:21).

Yet, toward the beginning of my hospital stay in September, not only did hospital staff converse with my mother, which I strictly forbid, they took suggestions from her. They even suggest to her, as well as my father, that she might have to become my substitute decision-maker should I become incompetent:

"*[Madison's mother] did inquire about MRI to rule out physical problems that may have contributed to Madison's presentation. A CT head will be done in this regard. Madison's parents are willing to become her substitute decision maker if it comes to that*" (Psychiatrist Progress Note; September 4th, 2021, 16:01).

While I had few 'delusions' about my father, he also said things to hospital staff that should have alerted them to the nature of our oft-tumultuous relationship:

"[Madison's father] stated the patient "should live in a facility" (Social Work Daily Documentation; September 10th, 2021, 15:24).

Though my father said concerning things about controlling my environment, such as the below statement, being discharged to my parents' home was considered the only feasible option for me, given that I could not afford a care home. Notably, I ended up taking myself to a homeless shelter for women facing abuse months after these events, and I was supported there in ways that respected my privacy, autonomy, and dignity.

"…[Madison's] father wants to restrict Madison's internet and communication with [her boyfriend] and other people" (Mental Status Exam; September 13th, 2021, 19:07).

Through these brief excerpts, I have demonstrated an incongruency between the perceptions of my hospital care team and myself. I have shown that despite a consistent theme of fear and distrust of my mother in my strong beliefs, and a growing distrust of my father, these feelings are ultimately rejected and dismissed by hospital staff as 'delusions,' even as they admit to having difficulties interacting with my mother. This lack of trauma-informed care on behalf of the hospital led to my extreme distress, paranoia, and distrust. To show the damage of not taking a patient's perspective into consideration, I choose now to put citations and records aside to speak with my own words.

Ahmad

Ahmad, another name for the prophet Muhammad—meaning one who is praiseworthy. Meeting my long-term partner, Ahmad, The One Who is Worth All My Praise, was like eating honey off a graham cracker—a favourite childhood snack of mine. Our love for each other is spread across different religions, genders, sexualities, and races, but I feel like I have met him and known him many times and in many places, and no matter how different we have been as people, we have always seen eye to eye, toe to toe, cheek to cheek. So, when I lost him, as I imagined I did, the screams that ripped through my throat felt like throwing up sandpaper. I do not remember exactly how it all started, but it involved my mother: while I was stuck in the hospital, I thought my mother had convinced Ahmad that my psychotic state was his fault and that she had pushed him to commit suicide. Safe and sound, Ahmad had no idea that I was mourning his death. At some point in my seemingly spontaneous screaming and crying, someone, likely a nurse, handed me a phone, and Ahmad was on the other line. This was probably one of the only times when I did not know if I could trust his voice or if he were real. This ‘delusion’ of his death was so strong, so intricately tied to every piece of my life. It was one in a long line of strong beliefs, each growing seemingly larger and scarier than the last until this one came along and stole everything from me—my sense of peace, of safety, of hope. I can only write about it because I know that there are other psychotic people who must have gone through similar experiences, and I know they need a voice, so I will keep using mine.

Unfortunately, this strong belief repeated itself. I imagined that Ahmad died at least six different times, each time just as gut-wrenching, just as heartbreaking as the previous experience. Some of these instances occurred in the hospital, and some of them continued even after I went home. A core theme of all my strong beliefs was my mother ruining my life through control, and this ‘delusion’ followed that same path. It made me hypervigilant, warning everyone and anyone that Ahmad could be in danger. My personal community therapist would later tell me, a year or so after my time in the hospital, that my mother joked to her sarcastically that “Ahmad died at least 20 times” while I was psychotic. The same woman who birthed me, who overheard my sandpaper screams—finding humour where I saw only despair. I wonder if she knows or if the hospital staff knows that the grief, the fear, has never completely left me. Every time Ahmad takes an airplane, every time my text message to him does not go through right away, my heart bullets out of my chest and eats me alive, like a hunting animal. Yet, according to multiple psychiatrists, I do not meet the criteria for post-traumatic stress; to them, I have only been ‘paranoid’—not in danger of real stress, real grief. My hospital records do not even mention how frequently and how violently I descended into fits of screaming and crying, begging for Ahmad back. Swept away, like sandcastles lost to the ocean's tides, my genuine and startling emotions did not make the cut for a clinical record. If I could have my clinicians understand only one thing, it would be that in my nightmares, my screams still taste like sandpaper.

Case Studies

In exploring my ideas on psychosis, I will look at specific case studies of groups of Mad individuals and how clinicians treat them. For example, I will highlight how clinicians tend to treat the 'symptoms' of psychosis rather than underlying patient distress or only look at psychoses through a highly biomedical lens, imagining illness where there is only crisis. In my first case study, the outcomes for mothers with postpartum psychosis are explored. In my second case study, the application of schizophrenia diagnoses to Black activists and hospital patients as a form of violence at the end of the Jim Crow era will be explored. Finally, in the third case study, the treatment of migrants and refugees by the European mental health care system will be explored.

Childbirth & Postpartum Psychosis

Characteristics of Postpartum Psychosis

Postpartum psychosis, which may also be shortened to PPP, is a rather rare condition that affects every 1 to 2 women out of 1000 (Hatters Friedman et al., 2012). It is important to note that transgender or nonbinary people who do not identify as women may be able to become pregnant and birth children and thus can experience this condition. At times, I will refer to 'mothers' to mean parents who are capable of giving birth. At times, I will reference 'women' who have experienced this 'disorder' because the only available research has focussed primarily on women. This is not meant to be exclusionary. As these terms and concepts evolve, so will I.

Notably, a list of clinical ‘symptoms’ for this condition can include “…hallucinations, delusions, mood lability, impaired insight and judgement, memory impairment, and altered sensorium resembling delirium” (Miller et al., 2014, p. 479).

Postpartum psychosis can have a negative impact on psychosocial well-being, as well as affecting long-term functioning—resulting in feelings of “…guilt, loss, fear, and shame” (Forde et al., 2020, p. 597). One interesting feature of this condition is that the severity of experiences may wax and wane more than in other psychotic episodes, with ‘symptoms’ appearing and disappearing suddenly (Spinelli, 2003). This may lead to a new mother who previously seemed well becoming rapidly unwell. Despite the severity of these experiences, mental health care professionals may find it hard to reconcile that a mother’s condition could change so spontaneously, chalking new changes up to expected feelings that come with new motherhood, such as inadequacy (Spinelli, 2003).

Stress

Saliently, it seems new mothers who are vulnerable due to pregnancy complications or stressors are most at risk of developing PPP, matching up with my earlier dialogue on psychosis and trauma (Aas et al., 2020). For example, mothers with postpartum psychosis or at risk for postpartum psychosis had a higher likelihood of experiencing physical symptoms during or after pregnancy (Aas et al., 2020). On top of experiencing physical problems, mothers with PPP reported stressful life events more often during or close to their pregnancy, typically resulting in higher cortisol levels (Aas et al., 2020). Cortisol, a hormone released by the kidneys, has an important relationship with stress (Aas et al., 2020). For example, higher cortisol levels and stress are linked with more severe ‘symptoms’ and a poorer ability to cope in regards to PPP, which suggests “…stress may represent an important underlying pathophysiological mechanism in [its] onset" (Aas et al., 2020, p. 5). This underlines the vulnerability of mothers experiencing postpartum psychosis—they are more likely to have a strenuous time during or near their pregnancy. Furthermore, mothers with PPP are more at risk of being socially isolated or lacking support (Spinelli, 2003).

Clinician Inattention

Most mothers and family members who encountered PPP reported being provided with little to no information about the illness within their prenatal care, leaving them feeling unprepared and deterring the opportunity for preventative care (Forde et al., 2020). This lack of focus on PPP in prenatal care may be due to an absence of research on the topic. As psychiatrist Margaret Spinelli writes, "The scarcity of contemporary research and literature on childbirth related psychiatric diagnoses available to mental health and legal professionals leaves room for great doubt that the system is functioning justly or effectively or humanely" (2003, Introduction). Furthermore, the DSM-III excluded postpartum psychosis as a diagnosis, as well as in subsequent publications, despite its inclusion in the first and second publications of the diagnostic manual in 1952 and 1968, respectively (Spinelli, 2021). Following the removal of PPP from the DSM-III, in the DSM-IV and DSM-V, the specifier of 'postpartum' was added for some diagnoses, published in 1994 and 2013, respectively (Spinelli, 2021). Unfortunately, this negatively impacts new, unwell mothers; as one study states, "A formal diagnostic classification of PPP provides the necessary clinical utility to prevent morbidity and mortality and diminish prolonged incarceration for young mentally ill mothers" (Spinelli, 2021, p. 821). Evidently, removing postpartum mental illness from the DSM has potentially devastating implications for unwell mothers as the validity of their illness and the weight of their 'symptoms' are not as readily recognized, which can affect the quality of their care or their likelihood of violence, which will be discussed next.

An Untold History of Women's Psychotic Violence

As written in *The Nature of Their Bodies: Women and their Doctors in Victorian Canada*, "Women [in the Victorian era] were discharged unimproved marginally more than men, perhaps because even when ill they were easier to control at home" (Mitchinson, 1991, p. 332). This speaks to how women can be cycled through the mental health care system, presumably due to appearing more 'calm and in control' than men, as Ussher states, and so being released without proper treatment for their underlying conditions (2011). Violence in the case of postpartum psychosis, however, is not new. Take, for example, the case of Emily Connors, admitted to a Canadian asylum in 1870 after she accused her husband of cheating on her and trying to poison her; she subsequently tried to kill herself, her child, her husband, and an attending nurse (Mitchinson, 1991).

Unfortunately, the proportion of women who are violent while psychotic is an underserved population when it comes to clinical research. For example, one study states, "…women have been excluded from much research in the field [of violence in psychosis], or, when they are included, information about them is not provided separately, or their numbers are so small that their data are not analysed" (Taylor & Bragado-Jimenez, 2009, p. 56). As the study goes on, "In spite of growing interest in the likelihood that women with psychosis who are violent have special treatment needs, there is little research to guide service specificity" (Taylor & Bragado-Jimenez, 2009, p. 62). Additionally, violence in the case of psychotic women is not especially rare, as another study explains, "Almost a fifth of this sample of 304 women with severe psychotic illness committed assault during 2 years of follow-up" (Frances, 2007, p. 267).

It seems like tragedies, such as mothers committing infanticide, could be avoided if more clinical attention was paid to the nature of PPP and violence within women, which are not new phenomena. Next, another example of clinician inattention to the gravity of postpartum psychosis comes in the form of the misdiagnosis or failure of proper diagnosis of underlying bipolar disorder.

The Occurrence of Bipolar Disorder

Women who have been diagnosed as having bipolar disorder are at a higher risk of developing postpartum psychosis, according to researchers, and postpartum psychosis may be the first appearance of bipolar disorder (Hatters Friedman et al., 2012). Approximately 26% of women with bipolar disorder will experience postpartum psychosis after childbirth, in which ‘symptoms’ typically appear within three weeks (Miller et al., 2014). Furthermore, a range of about 49%-67% of new mothers with bipolar disorder will experience postpartum mood disturbances (Miller et al., 2014). What this means to me is that a specific group of disabled or ‘ill’ or disadvantaged women are most likely to develop postpartum psychosis. Thus, failures to adequately address postpartum psychosis or bipolar disorder will run the risk of ableism as clinicians apparently lack the quality of care and understanding necessary for recognizing how specific women are impacted by these ‘illnesses,’ as will be discussed in the next section.

Misdiagnosis and Mismanagement of Bipolar Disorder

Although having been around for over 2000 years, bipolar disorder is often diagnosed late or not at all, and since bipolar disorder is typically classified as a psychotic ‘disorder,’ this can have undue outcomes for those who have it (Meyer & Meyer, 2009). For example, the misdiagnosis of bipolar disorder is associated with a high risk of suicide attempts, prolonged hospitalizations, and significant psychosocial, financial, and legal issues (Meyer & Meyer, 2009). Furthermore, a misdiagnosis of bipolar disorder may lead to inappropriate or ineffective treatment, such as the absence of a prescription for mood stabilizers when medication is desired, which are known for their effectiveness in treating bipolar disorder (Meyer & Meyer, 2009). Similar to other ‘illnesses,’ there is a delay in the diagnosis of women compared to men; for example, “Women with bipolar disorder were misdiagnosed with unipolar depression for 1.9 years longer than men, and started maintenance treatment 5.5 years later on average” (Miller et al., 2014).

Some features of bipolar disorder that are unique from major depressive ‘disorders’ include “atypical features of depression (e.g., hypersomnia, hyperphagia), depression with psychotic features, early onset of the illness, more frequent episodes, and a poor response to or a failure to maintain response to antidepressants” (Sharma & Khan, 2010, p. 338). Having a poor response to antidepressants is particularly salient in the treatment of bipolar disorder. What is especially important in understanding bipolar disorder is that “Physicians may fail to appreciate the possibility of a bipolar diathesis in PPD and prescribe antidepressants that may lead to induction of (hypo)manic or mixed episodes” (Sharma & Khan, 2010, p. 336). Notably, manic episodes may lead to or occur with psychosis, as is what happened in my case. As one study importantly explains, “Caution should be exercised regarding the use of antidepressants in patients with a suspected bipolar diathesis” (Sharma & Khan, 2010, p. 338).

Clinicians who treat women with postpartum psychosis often seem to miss that “Since the postpartum period is also a time of high risk for the occurrence of manic symptoms, patients presenting with an episode of postpartum depression [or psychosis] should be carefully evaluated for a bipolar diathesis” (Sharma & Khan, 2010, p. 338). Yet, of course, even if there is a screening for bipolar disorder, misdiagnosis is still common for women. As a genderqueer woman, for example, I visited four male psychiatrists over a period of several years and received multiple different psychiatric diagnoses, such as ‘major depressive disorder’ and ‘unspecific psychotic disorder.’ None of these diagnoses seemed to capture the full weight of my experiences until I finally received the conclusion from a female psychiatrist that I was dealing with bipolar disorder, which I find most accurate—even as I question the nature of mental ‘illnesses.’

Appearing Mentally Ill

On historical insanity in women, Mitchinson writes that based on appearances, it was unconvincing to physicians that women had symptomology that warranted committal or a diagnosis of insanity (1991). Furthermore, in *The Madness of Women*, Jane Ussher writes, “Hegemonic constructions of idealised femininity in Western culture place particular emphasis on women being calm and in control (as well as slim), with deviations from this norm being positioned as pathology” (2011, p. 158). With the waxing and waning nature of postpartum psychosis, mothers may choose to check into medical facilities on days or at times when they are feeling, and most importantly *presenting*, most functional, decreasing their chance of being pathologized (Spinelli, 2021). While clinical over-pathologizing is certainly a concerning topic discussed in this paper, pathologizing in the case of extreme distress may provide answers or treatment that prove useful, even if there are more desirable outcomes. Yet, with clinicians not receiving training on how to identify postpartum psychosis, especially to screen for bipolar disorder in the case of postpartum mood disturbances, the picture becomes clearer on how too many women have slipped through the cracks. Another instance of clinical misjudgment in the face of psychosis will be discussed next: how clinicians may stereotype and stigmatize their psychotic patients.

Stigmatization

While the lack of clinical research and attention toward postpartum psychosis may negatively affect suffering mothers, so might stigmatization. Fear of consequences and stigmas leads to psychotic mothers delaying seeking help for their distress, which may be associated with fears of losing their baby (Forde et al., 2020). Unfortunately, "…women often reached [a] crisis point before seeking help," which may also be true for new parents with postpartum psychosis who do not identify as women (Forde et al., 2020, p. 608). Generally, when it comes to psychosis, negative stigmas are common; a review of qualitative literature on service user perspectives found that stigma in their social systems is pervasive (Burke et al., 2016). Furthermore, encountering stigmas can inevitably lead to: "…social exclusion, devaluation of difference, lack of power and control, lack of understanding, stereotyping and discrimination, inferiority and inequality, shame and secrecy and pessimism about recovery" (Burke et al., 2016, p. 130).

Mental health clinicians may be the perpetrators of stigma, although following a thorough literature review, research on this topic is notably sparse. One available study, for example, determined that clinicians believed individuals with serious 'mental illnesses,' especially schizophrenia, are much more likely to exhibit violence compared to those without mental illnesses, even though psychotic or schizophrenic individuals are more likely to be victims of violence than they are to commit violence (Stone et al., 2019; Jones & Shattell, 2014). Interestingly, mental health professionals also wanted distance from seriously 'mentally ill' individuals in their personal lives (Stone et al., 2019). For example, "…one study [indicated] that 100% of nurses would not like their sister marrying someone with schizophrenia" (Stone et al., 2019, p. 675). Perhaps it is no wonder that mothers experiencing postpartum psychosis wait until a crisis point to seek help if they recognize that the mental health care systems available to them are rife with harmful stigmatization.

A Mother Who's Been There

"Postpartum psychosis must be the most cruel, twisted joke Mother Nature could ever play, and probably on the list of the world's best-kept secrets," says Jane Lowry, a stay-at-home mother who experienced the condition (Nunes et al., 2004, p. 91). Although I do not have children, her experiences eerily remind me of mine, especially her thoughts while staying in the hospital. "I doubted that any of the doctors were real doctors, and the nurses didn't seem like real nurses. In fact, even the patients seemed as if they were reading lines from a script..." (Nunes et al., 2004, p. 93). Notably, in my medical records, I report to a social worker that it seems as though people are 'talking like robots.' This belies the mistrust and fear that accompanies psychosis, and in survival mode, you have less time to think things through, to understand—how can you when there is danger afoot? As Jane says herself, "I was under twenty-four hour surveillance with the latest in satellite technology, which meant my every action and word was monitored. *They* could see through the walls of our house. I was a prisoner" (Nunes et al., 2004, pp. 93-94). As larger-than-life as these experiences can be, they are preventable. As Jane succinctly puts it, "If postpartum psychosis were not such as 'shhhh, don't scare the pregnant women' issue, the potentially vulnerable one-in-a-thousand mothers who endure it would have a better chance of receiving proper treatment right away and avoiding an experience like mine" (Nunes et al., 2004, p. 96). For new or potential mothers, providing them with factual, comprehensive knowledge, such as risk factors for PPP, and supplying them with high-quality prenatal care, can make all the difference in the world.

'Protest Psychosis' – 1960s & 1970s

As a White graduate student, I do not experience institutional or individualized racism; in fact, I have participated in and benefitted from systems of racism. Admitting these things does not right them, but I believe that it is inappropriate to participate in dialogues on racism as a White person without acknowledging your social position in systems founded through racism and colonialism, such as the mental health care system in the United States or Canada, or the greater Western world. For example, even when I was considered out of control enough to be suicidal or even homicidal when I was psychotic, I was never restrained. I was asked politely to follow a police officer to his car to be transported to the hospital. After the police officer left me in the emergency room, he commended me for being “nice and good.” A homicidal psychotic. Maybe my words were taken out of context, maybe I was simply frustrated and confused, and that was taken to mean aggressive or dangerous, as would be characteristic of how psychotics are treated. Yet, those labels did not stick as my time in the hospital progressed.

As a White woman, I was given the room and the chance to prove myself otherwise, even as I hated every moment of my confinement. What I will discuss next is how psychiatry has not given that same chance to Black American men, specifically in the rise of the Civil Rights movement in the 1960s. But there are countless examples of the horrific mistreatment of Black people in the Western world, many of which persist today, even though I narrow in on only one of them. See, for example, my brief discussion of ‘drapetomania’ on page 36. What I will discuss next is disgusting malpractice, ignorance, and belittlement. While I do not have all the answers to systemic problems, I know that White people, myself included, are not asking enough questions, challenging enough standards, making enough room for marginalized voices, or confronting enough assumptions to incur change. Who taught me this? Why do I think it is true? Who could benefit from my thinking or acting this way? Who is left out? Who is left out? Who is left out?

That question rang like a bell in my ears as I wrote about this topic, and may it always ring, so long as pity is served when it is justice that was requested.

The Racial History of Dementia Praecox and Schizophrenia

As will be demonstrated in this section, "...the material reality of schizophrenia is shaped by social, political, and, ultimately, institutional factors in addition to chemical or biological ones" (Metzl, 2011, Preface). In earlier days of identifying psychotic disorders, the set of experiences we know as 'schizophrenia' originally went by another name—dementia praecox—named and characterized by German psychiatrist Emile Kraepelin in 1899 (Metzl, 2011; Kendler, 2020). It was not until 1911 that Swiss psychiatrist "…Eugen Bleuler's major monograph on schizophrenia had been published…" which differed in some ways from Kraepelin's dementia praecox but shared characteristic 'symptoms,' such as 'hallucinations' (Kendler, 2020, p. 635). Notably, "Kraepelin believed that dementia praecox was a biological illness caused by underlying organic lesions or faulty metabolism" (Metzl, 2011, p. 28). Bleuler disagreed with Kraepelin in several key ways: he noticed that praecox was not a dementia and that it could occur in older people, not just developing in youth, as Kraepelin thought (Metzl, 2011). Furthermore, Bleuler believed the basis of the disorder was a "loosening of associations" or a splitting of the personality, unlike Kraepelin's biological basis (Metzl, 2011, p. 28).

Ultimately, the term schizophrenia prevailed over dementia praecox: "Historians of psychiatry often assert that schizophrenia replaced praecox for clinical reasons...Bleuler's definition more adeptly encapsulated the prognostic trajectory, and the free market of medicine invested in the accurate term while devaluing the inaccurate one" (Metzl, 2011, pp. 29-30). Unfortunately, however, when the terms dementia praecox and schizophrenia travelled from Europe to the United States in the early 1900s, the nosology of the illnesses became warped by eugenicist ideas that persisted in American culture at the time (Metzl, 2011). Jumping at the biological basis behind Kraepelin's dementia praecox, "American popular culture…associated Kraepelin's schema with marginalized others…and practically every mention of the illness in major American newspapers between 1910 and 1930 referenced the term in relation to anxieties about 'Negroes,' immigrants, criminals, or 'subnormals'" (Metzl, 2011, p. 31). Conversely, schizophrenia had its basis in the personality of the mind, and as such, "Psychiatrists instead described patients with schizophrenia as academics, poets, women, eccentrics, and others who perhaps deviated from, but remained largely within, the norm. In sharp contrast to dementia praecox, schizophrenia often implied an illness not of the black body, but of the white mind" (Metzl, 2011, p. 34).

Time would eventually change the illness, but from the 1920s to the early 1950s, "Schizophrenia often appeared in popular magazines and newspapers as a personality disorder brought by the pressures of white civilization..." (Metzl, 2011, p. 36). Additionally, American psychiatrists, such as Noyes or Betz, talked about their schizophrenic patients as if they had regressed to a childlike state and could be helped if they were taught and nurtured "how to function as adults" through activities like occupational therapy or physical exercise (Metzl, 2011, p. 36). "Schizophrenia connoted emotions and personalities and intellects…" and so, it perhaps felt safe or natural to diagnose any disobedient, yet ultimately harmless, White person with the illness (Metzl, 2011, p. 34). Furthermore, since diagnostic categories for mood disorders were rather small at the time, "Schizophrenia…was a term as wide as The Grand River Valley. The term made room for depressives, the too-neurotics, the paranoids, hallucinators, delusionals, and katatonics" (Metzl, 2011, p. 41).

As mentioned, however, these diagnostic trends would not continue; the 1960s brought particular changes in how and with whom schizophrenia was diagnosed (Metzl, 2011). Accordingly, “From the 1960s onward, patients described by doctors as African American, paranoid, delusional, and violent had disproportionately high chances of being diagnosed with schizophrenia…” whereas White patients with more tearful, ruminative, or ultimately ‘harmless’ dispositions were most likely to be diagnosed with anxiety or mood disorders (Metzl, 2011, p. 57). Following these trends, I will explain “…how perceived racial differences change radically over space and time, and convey different meanings in different social or historical contexts” (Metzl, 2011, p. 59). Additionally, in line with my theorizing on psychosis, I will suggest how necessary coping mechanisms developed by Black Americans in the context of racism, colonialism, and capitalism were warped in the 1960s into the symptomology of an ever-changing illness—schizophrenia.

Stereotypes, Diagnoses, and Metaphors

The historical, yet still present, racism in mental health care mentioned above is only a minuscule portion of what has been put forth. See, for another example, American physician Samuel Cartwright’s creation of ‘drapetomania’—a supposed mental illness experienced by enslaved Black people in the American South, which would apparently compel them to run away from the horrific conditions of bondage—first introduced in 1851 (Fernando, 2004). Cartwright’s idea may be reflected on today as absurd, but it was undoubtedly influenced by the times and places in which he lived, which helps to demonstrate how mental illnesses are intricately tied to the subjective views, positions, and assumptions of the people with the power to define them. Racist, misconstrued ideas about the mental states of Black people, like Cartwright’s drapetomania, did not go away, however—they have merely shifted over time.

As British-Sri Lankan psychiatrist Suman Fernando, Honorary Professor of Social Sciences and Humanities at London Metropolitan University, writes, assumptions, stereotypes, and misunderstandings about Black people, as well as other non-white or non-European ethnic groups, influence diagnostic practices, resulting in the topic of interest: the overdiagnosis of schizophrenia for Black American men (Fernando, 2004). Although I focus here on the context of the mental health care system of the United States in the 1960s and 1970s, similar diagnostic trends for schizophrenia among Black psychiatric consumer survivors are demonstrated in other Western countries, such as the UK (Fernando, 2004). Notably, in 1968, psychiatrists Bromberg and Simon described a phenomenon they called ‘protest psychosis,’ in which they believed that "…the rhetoric of the Black Power movement drove ‘Negro men’ to insanity" (Metzl, 2011, p. 100). Accordingly, a relevant study from 1951 found that many psychiatrists had difficulty assessing the emotions and behaviours of Black patients "…because of mutual mistrust and hostility between racial groups," yet this does not excuse or explain the act of racism; it does, however, elucidate sociopolitical tensions that were rising in the United States at the time (Fernando, 2004, p. 34).

Furthermore, "Bromberg and Simon's central contention, that participation in civil rights protests caused violent schizophrenic symptoms in ‘Negro populations’ in ways that threatened ‘white’ civilization, appeared in various forms in many other mainstream psychiatric research articles in the 1960s and 1970s" (Metzl, 2011, p. 101). Other psychiatrists, such as Eugene Brody, followed suit, claiming that simply being Black was a risk factor for schizophrenia (Metzl, 2011). As such, the pharmaceutical industry saw its opportunity to market antipsychotic medication to White doctors with "racial anxieties," using depictions of African tribal masks and artifacts in Stelazine ads, for example, throughout the 1960s and 1970s (Metzl, 2011).

Meanwhile, certain popular American media outlets, such as the *New York Times* or the *Los Angeles Times*, sought to "pathologize protest [and] the prospect of radical social change," while Black-run newspapers aptly explained that racism was and still is a catalyst of Black Madness (Metzl, 2011, p. 118). Findings from clinical research come to a similar conclusion, in that discrimination is a "toxic stressor" that influences the positive likelihood of lifetime psychotic experiences (Oh & Anglin, 2023).

Far from being just a supposed illness or diagnostic category, schizophrenia or 'protest psychosis' functioned as a metaphor for race relations in the 1960s and 1970s in the United States. As Johnathon Metzl puts it, "Schizophrenia in this context was both a mental illness with tragic material effects and a pernicious cascade of self-perpetuating stereotypes in which observations about 'race' and 'diagnosis' stood in for a host of other charged assumptions and anxieties" (2011, p. 154). In a disturbing example, many leaders of movements like Black Nationalism or the Nation of Islam were diagnosed with schizophrenia by the FBI in a belittling attempt at marking their resistance as insanity (Metzl, 2011). In particular, the FBI diagnosed Malcolm X with "pre-psychotic paranoid schizophrenia" in now de-classified documents (Metzl, 2011, p. 122). Yet, simultaneously, it was not just White people who associated schizophrenia with Blackness; in one example, pastor and civil rights leader Reverend Wyatt Tee Walker believed that schizophrenia persisted within the Black community as a common condition, specifically as a response to the racist White society surrounding it (Metzl, 2011).

These diverging, and sometimes converging, influences from the Civil Rights-era on the pathology of Black male mental health still exist today; for example, one study from the early 2000s found that although different ethnic groups experience schizophrenia at the same rate, Black American men were four times as likely to be diagnosed with schizophrenia than White patients (Metzl, 2011, Preface). Furthermore, “African American men also receive higher dosages of antipsychotic medication than do white male psychiatric patients, and are more likely to be described by health care professionals as being hostile or violent” (Metzl, 2011, Preface). While I have briefly discussed misunderstandings, assumptions, and stereotypes as potential explanations for how psychiatry operates in its treatment of Black American men, there is frankly no excuse for erasing or ignoring the voices of Black community members and leaders who have clearly discussed the racism of a White society as a consistent underlying current for Black hostility, anger, paranoia, or even Madness. There is also a complex relationship between the over-pathologizing, overmedication, and over-incarceration of Black men, which must be further explored (Richardson et al., 2020).

Loose Ends – Do Not Tie Them

Though the pathologizing of Black American men has been the topic of discussion here, the absence of Black American women does not mean they were free from harm; in fact, “...the absence of African American women in medical treatment narratives suggests that, for better and mostly for worse, these women suffered in silence” (Metzl, 2011, p. 61). For Black women and Black queer, trans, and intersex people, who are not necessarily exclusive groups, how are they treated by the psychiatric system, historically and presently? How do they navigate? How do they heal? We have discussed Black hostility and anger toward White authority specifically, but this is a picture of Black American men painted by a White interrogative gaze. How would these men describe themselves? In many cases, though these men had their own thoughts and opinions, they were not recorded, not privileged, or not given the benefit of contextualization—they need to be. As Therí Alyce Pickens writes, “No one can end a discussion about intertwined Blackness and madness neatly, if at all” (Pickens, 2019, Preface or About Face, Giving Face). Perhaps because there is so much left unsaid, so many stories left untold… So, I will leave this section with ambiguity, I will not tie loose ends together and decide how the story ends when I have been given a voice and others have not. I will likely leave you here with more questions than answers. *Who is left out?* Perhaps they are questions that need asking. *Who is left out?* May they ring like bells for you. *Who is left out?*

Psychotic 'Illness' in Migrant and Refugee Populations

A European 'Crisis'

The year 2015 saw an unprecedented increase in the number of migrants coming to the European Union, and while certain countries like Germany initially offered them a 'warm welcome,' the political atmosphere shifted as migration rates continued to remain high, and a sense of political and public 'crises' began developing (Slominski & Trauner, 2017). Thus, reducing the number of migrants and refugees or returning them to their home countries became a primary concern across Europe, which continues today (Slominski & Trauner, 2017). Notably, the framing of these events as a 'crisis' is "…largely a construction of media and political discourse that serves political ends," as White-majority European states use the guise of crises to block migrant arrivals (Desmond, 2023, p. 317). In some cases, EU Member States are willing to breach laws and risk lives directly to shirk their responsibilities for accepting migrants and refugees (Desmond, 2023). For example, in 2020, "…pandemic-related port closures by Italy and Malta resulted in migrants being stranded at sea…and arguably fell foul of international human rights and maritime law and international health regulations" (Desmond, 2023, p. 327). Measures such as these have led to dangerous and lethal border crossings in the Mediterranean Sea, which have turned the "…maritime borders of Europe into a macabre deathscape" (De Genova, 2018, p. 1766).

To be blunt, thousands of lives have been lost while European policymakers tediously debate their options and opinions back and forth on appropriate policies to ameliorate the 'crisis' (Amenta et al., 2021). At the same time, there have been concerns over low birth rates and declining populations across Europe for several decades, and it would seem that the arrival of migrants and refugees came at an opportune time—were it not for the disgusting racism that surges across the European continent just as the Bubonic Plague once did (Keilman, 2008). Within this 'crisis' or 'epidemic,' political and public attitudes continually construct a sense of 'antagonism' between White Europeans and the arriving migrants and refugees, who are frequently people of colour (De Genova, 2018). Bringing with them a startling diversity of cultures and a distinct 'non-Europeanness' in the eyes of pearl-clutching White Europeans (De Genova, 2018).

In one article, scholar Enrica Rigo discusses a young Nigerian woman whose story gave perspective to the experiences of migrants and refugees crossing to Europe; for example, "[The young woman] had also offered to carry the children of the women who were travelling with her because she thought that if she looked like a mother, she would be less exposed to sexual and other forms of violence. In fact, while on the first journey[,] she had been sexually assaulted…" (Rigo, 2018, p. 508). While migrants and refugees frequently seek to escape tragedy or instability in their home countries, they are thrust into more tragedy and instability by unsympathetic White Europeans who bend laws and risk lives to expel them. Soon, we will discuss what these emotional and physical tolls must put on a person and how attempts at managing to cope with extreme circumstances are often looked at through a biomedical lens. First, the state of health care, particularly mental health care, for migrants and refugees within Europe.

Migrant and Refugee Healthcare in Europe

Migration may be considered a social determinant of health for several reasons, including its association with social marginalization and loss, among other factors (Gkiouleka et al., 2018). Each EU Member State has notably recognized the right of each individual to attain the best standard of physical and mental health care available, yet this does not necessarily extend to migrants and refugees (Lebano et al., 2020). Unfortunately, despite the EU Member States' recognition of the right to healthcare, "…inequalities persist in access and use…" for migrants and refugees across Europe (Lebano et al., 2020, p. 8). Lack of funding and language and communication issues are just some of the factors negatively influencing the ability of migrants and refugees to access equitable healthcare (Lebano et al., 2020). Mental health for migrants and refugees is of significant interest due to psychosocial stressors faced in their host countries, including discrimination and rejection, which "…seriously harms their wellbeing" (García-Cid et al., 2020, p. 2; van der Laan et al., 2020). Evidently, the situation of addressing migrant and refugee mental health care is complex, and it is perhaps compounded by the "...lack of reliable, standardized and shared procedures for routine collection of health data on migrants in European member states…" (Lebano et al., 2020, p. 8).

So far, this discussion may seem to presume that migrants and refugees want to or should treat 'mental health issues' through European health care services, and this is not necessarily the case. For example, "…the tradition of recognising illnesses or disorders of the mind and providing 'therapy' for them…is not evident in medical traditions of Asia, Africa or pre-Columbian America" (Fernando, 2004, p. 89). If migrants and refugees would like to access European healthcare services, then they should receive the highest quality of care, as promised by the EU Member States themselves. If they would like to 'treat' presumed illnesses in a different way, perhaps in a way traditional to their culture of birth, then that should be honoured. What we have found so far, however, is that the wishes of psychiatric service users are not necessarily respected, and this is even more true the more unwell the person becomes or the more they deviate from White, Western values. In the context of psychosis among migrant and refugee populations, this story is no different. Later, I will discuss specific patient movements of rebellion within the contemporary Mad Movement, and we will have time to revel in being Mad. For now, we must discuss the harm that is being done to seriously unwell individuals.

Diagnosis and Research of Psychosis in Migrants and Refugees

The state of immigration policies in Europe, the lack of appropriate research on migrant and refugee mental health, and the overwhelming psychosocial stressors present for migrants and refugees create a troubling framework for understanding the dynamics of a particular mental health issue: high incident rates of psychosis and schizophrenia within these populations. The rate of developing psychotic disorders unequally affects migrants and their offspring in high-income countries; for example, the incidence in people of Black Caribbean descent is more than five times higher than that of the White British population in the UK (Jongsma et al., 2020). Yet, from a clinical standpoint, these increased rates of psychosis are unexplained despite nearly a century of research (Jongsma et al., 2020). Research may not be progressing forward, according to Suman Fernando, because researchers are glued to Western cultural concepts and biomedical models of mental 'illness,' while ignoring ideas from service users (Fernando, 2004).

In the US, it is oft reported that the high rate of schizophrenia diagnoses for Black American men is a result of overdiagnoses, yet in countries like the UK, the mechanisms behind high diagnosis rates for migrants and refugees seem more disputed (Jongsma et al., 2020). For example, take the work of Selten & Sijben, who analyzed "…first admission rates for schizophrenia in the four largest immigrant groups to the Netherlands (from the countries of Surinam, the Netherlands Antilles, Turkey and Morocco)" (1994, p. 71). In finding that certain immigrant groups had higher incident rates of psychotic disorders, the authors conclude that "It is unlikely, however, that…diagnostic bias explains our findings" with no explanation for this assumption, removing accountability for mental health care professionals (Selten & Sijben, 1994, p. 75). A more recent study from 2020 also concluded that overdiagnosis is not a possible explanation for excessively high rates of psychotic disorders diagnosed in particular minority ethnic groups in England, even though the authors primarily cited decades-old studies to support their claim (Jongsma et al.).

Furthermore, this clinical research out of the Netherlands and other Northern European countries seems preoccupied with determining which ethnicity is most at-risk for schizophrenia or psychotic disorders, which seems rather like eugenics (Fernando, 2004; Selten & Sijben, 1994). As Suman Fernando astutely writes, "The question must be asked as to the usefulness of all this research and what the real (hidden) agenda may be. Why this apparent relentless search…when the system of diagnosis itself is not being questioned? Why carry on counting 'schizophrenics'?" (2004, p. 41). Perhaps there is a rush to research and pathologize psychotic persons from minority ethnic groups in another attempt to limit migration from certain countries. Why else consistently highlight that minority ethnic groups have higher incident rates of schizophrenia and psychotic disorders yet consistently fail to provide adequate explanations behind this phenomenon? A century of 'thorough' research goes down the drain.

Psychiatrists and other mental health professionals would prefer their patients to think they must endure 'biological abnormalities' that seem inaccessible to treat rather than letting them explore and ultimately come to peace with their 'complex and significant' experiences like voice hearing (Fernando, 2004, p. 131). Notably, the study by Jongsma et al. elicits that psychosocial disempowerment, in which migrants are exposed to significant "…social or cultural barriers in achieving autonomy and control over one's environment," is a risk factor for psychosis (2020, p. 1545). As the study goes on, it elucidates the need to "…understand if [psychosocial mechanisms] are associated with neurobiological signatures relevant to psychosis" (Jongsma et al., 2020, p. 1545). The psychosocial thus becomes the biopsychosocial, as the conversation seems to imply that there are genetic deficiencies or predispositions that are likely to cause contributing factors in developing psychosis. Yet, why presuppose that these particular ethnic groups might have faulty genes, so to speak, when it has already been admitted that the social and cultural barriers they face are the significant psychosocial stressors at play? Instead of determining whose genetic makeup might react with negative environments the most, why not simply work on changing the negative environment?

Also of important note is the continual lack of agency assigned to migrants and refugees when discussing psychosis; according to the Jongsma et al. study, "Individuals without sufficient social, economic, political or cultural capital required to achieve autonomy and control over their environment are exposed to more risk factors for poor health outcomes including psychotic disorders" (Jongsma et al., 2020, p. 1537). In this way, migrants and refugees are posited as being powerless social actors in terms of their environment. In re-phrasing the statement from Jongsma et al., migrants and refugees navigate healthcare systems that are not designed with them in mind, learn languages that sound unlike their native ones, and attempt to vote strategically in political systems where their voices are not privileged. This new framing perhaps elucidates the strength and skill it takes to live as a migrant or refugee.

Lived Experience

In my research of relevant literature, I had a difficult time finding perspectives of migrants and refugees who have experienced psychosis. While certain authors have discussed the impact of a schizophrenia diagnosis on the experiences of migrants and refugees (see: Ameil Joseph), direct perspectives from these individuals are often missing (2014). Yet, we must listen to what migrants and refugees go through, even if they are not discussing psychosis directly. One study focuses on the resilience of Syrian refugees in the UK; for example, one participant explains how they maintain their resilience, “What helps me to not give up is that I say: when one sees other people’s suffering[,] he feels better about his own” (Alachkar, 2022, p. 135). Another person discusses how their faith has the potential to save them: “When I saw it with my own eyes[,] I realised that the chance of surviving would be no higher than 15%. But people are managing to cross the sea not with their own effort, but with God’s help” (Alachkar, 2022, p. 136). Through these brief excerpts, we can see not only expected shock and dismay but an attempt to move past or reckon with these undue circumstances. As the study on Syrian refugees aptly explains, “…responses to trauma that might seem pathological, such as PTSD, may be necessary and adaptive…” (Alachkar, 2022, p. 133). This calls into question once again the view of survival, of complex resilience, as pathology. By positing their means of survival as a mental flaw, are we not blaming migrants and refugees for the consequences of their suffering? Alternative ways of allowing individuals with psychosis to explore their experiences, such as hearing voices, are explored next.

Acknowledging My Own Voices

In my experience, I heard multiple different voices of presumed nurses following me around for roughly six months after I left the hospital in October of 2021. The voices gently faded when I was switched to a new anti-psychotic, Abilify, around March of 2022 after originally being put on Olanzapine in the hospital—which did nothing but gradually give me an insatiable hunger. While I was hearing these voices, ignoring them frustratedly and trying not to argue with them, I began working in a Housing with Supports mental health and housing program in which many clients had schizophrenia. Very few of them discussed hearing voices. Now, I work in an addiction treatment program, and I have also met several people who hear voices this way. Most of them who admitted to it were disturbed by the voices, as I was. In both programs, clients who admitted to hearing voices seemed to be targeted for hospitalization or at least made the program administrators antsy. Maybe because of this, it took me a year to admit to anyone what had happened to me, what I heard, even though it was suspected by family and mental health professionals that I was having 'auditory hallucinations.' Some people will never feel comfortable to discuss openly what they hear.

I remember my heart leaping when a classmate of mine in a Mad Studies class mentioned that there was such a thing as the Hearing Voices Network, with support groups for people like me. Although I still have not attended a Hearing Voices support group as of yet, I have attended support groups for both bipolar disorder and OCD, which have been immensely helpful in providing a sense of comfort and support. When someone tells you gently that they understand something about you that you thought was the deepest, most despicable, most uncontrollable part of you and tells you that it is okay that these things are happening to you, an immense wave of sadness, yet relief can wash over you. It makes me hopeful. It makes me want to tell the truth... I still hear flickers of voices. When I am most anxious, most stressed, I can feel myself imagining what they would say, laughing at me, poking at the things I do. Like echoes of something that once was. It is irritating sometimes, but I found that when I was fighting hard against the voices, trying to suppress them, the louder they became. Now, I can wave my hand at them, and they tend to go away. By talking about them, by coming to accept that they are simply something that happens to me sometimes, I have gained more control over them.

And that is what I think is needed: for psychotic people to feel like they can be open and truthful and unashamed of the experiences they go through. Hiding away, always trying to filter out what you see or hear, that cannot be 'healthy' under any definition of the word. That is why I think we need to find treatments beyond the biomedical forms of care that Western psychiatry offers now, as it has spent so much time poking and prodding at those most in need, as demonstrated in the case studies above. At the same time, if psychotic people do not want treatment, they should be able to have a say in their own care. To force a psychotic person into treatment simply because they seem scary or confusing to others is not a good enough reason to lock someone away. I was held in involuntary care because I was claimed to be 'suicidal' and 'dangerous to others.' As I have never harmed myself or anyone else, now or then, what proof did they have of this? Why does my hospital record not have an 'evidence' section? I am expected to accept these claims because they came from psychiatrists, who are given so much leeway in how they can dictate how others are supposed to act. The following sections of this paper will focus on alternatives to psychiatry. Relatively new or still emerging forms of care will be discussed in the next section, and the last section of this paper, before the conclusion, asks a vital question: do we need psychiatry? Did we ever?

Burgeoning Forms of Care

In 1978, psychiatric ex-patient and advocate Judi Chamberlin wrote the book "On Our Own" about 'patient-controlled alternatives to the mental health system' including types of care models based on the level of professional involvement (Chamberlin, 2012, p. 86). In this section, I will elaborate on these models and provide examples for models of care—although they are not necessarily forms of ‘treatment,’ which might imply medical intervention. First, the ‘separatist’ model might seem like the ideal, in which consumer survivors/ex-patients provide support for each other with the exclusion of non-patients and professionals (Chamberlin, 2012, p. 87). On the other hand, psychotic or Mad individuals will have to interact with others, most likely, while in distress. Not having a model for care or interaction with psychotic individuals in distress by nonpsychotic individuals is less than ideal. To some, it might seem obvious how to treat a person in distress—be kind, offer clear and simple options for care, do not pressure them—yet, sanism is pervasive and has clouded many minds on what being psychotic is like. It is usually disorienting and emotionally draining, and it involves experiencing time in fragments instead of only being about violence or unpredictability or instability. We need to set the record straight.

That is why I am including one burgeoning form of care that follows the ‘separatist’ model and one form of care that follows the ‘partnership’ model where, at least in theory, professionals and consumer survivors work together to provide a service (Chamberlin, 2012, p. 86). The first, separatist form of care is the Hearing Voices Network support groups, and the second, partnership form of care is what I have termed the ‘sensory-validating care,’ which is a holistic form of care I have compiled. It is partly based on the work of Naomi Feil, an American social worker who created ‘validation therapy’ for older adults who have Alzheimer’s-type dementia, Tamasin Knight, an English physician who compiled techniques for working with individuals who have strong beliefs, otherwise known as ‘delusions,’ and Marius Romme, who founded the Hearing Voices Movement that led to Hearing Voices Networks (Feil & Klerk-Rubin, 2022; Knight, 2013; Longden et al., 2017).

Hearing Voices Networks

Within the Mad Movement, since its rebirth, various patient groups and organizations have sprung up across the Western world, including the grassroots Mental Patients Association in Vancouver, Canada, during the 1970s, or the largely successful networks from the Hearing Voices Movement, originally started in the Netherlands in the 1980s (Boschma et al., 2014; Longden et al., 2017). This section will focus on the Hearing Voices Network, which started in England shortly after the founding of the Hearing Voices Movement out of the Netherlands (Longden et al., 2017). Currently, there are similar Hearing Voices Networks in over 30 countries across the globe, growing outward from England like an expansive mycelium (Longden et al., 2017). In England alone, there are over 180 different groups belonging to the Hearing Voices Network (Oakland & Berry, 2014). Importantly, meetings of the Hearing Voice Networks are typically facilitated by voice-hearers themselves, as opposed to professionals (Oakland & Berry, 2014).

Since they are led by groups of voice-hearers independent of professional involvement, the Hearing Voices Networks can be thought of as a form of peer support (Oakland & Berry, 2014). One qualitative study on the experiences of voice hearing in a Hearing Voices Network group listed the following themes found from an analysis of participant responses: a sense of hope about learning from others, ownership of the group, allowing for key values to be maintained, acceptance of individual difference and experience, learning effective coping strategies, and more (Oakland & Berry, 2014). As one participant, Richard, explained about feeling accepted, “You think that you're on your own for years and years and then all of a sudden there’s all these people round you who have experienced the same kind of thing as you” (Oakland & Berry, 2014, p. 124). A sense of inclusion is vital for voice-hearing people, some of whom are homeless, on disability payments, or in otherwise precarious situations—which tends to feel like being on the fringes of societal acceptance. As a previously homeless psychotic person, I felt like the whole world was looking down on me. In a support group, when feeling empowered, the world shifts—it falls to your feet, wondering how it could have misjudged you, how it could have ever made you feel so small. Even if this is only a perception, only a dream, it has the power to keep psychotic people afloat instead of barely treading water.

Another common theme that emerged from participant experiences in the same study is that they held anxiety about initially attending the group, but most ultimately decided that the benefits outweighed their fears (Oakland & Berry, 2014). For example, one participant, James, said, “It’s like a big step but it’s worth doing. You do share ways of coping,…it’s worth doing you know you'd be stuck in a rut anyway so you may as well try some ways to help yourself” (Oakland & Berry, 2014, p. 122). Another theme across multiple studies is that participants could gain meaning and insight into the voices they heard (Oakland & Berry, 2014; Payne et al., 2017). As a participant from one study, Helen, explained, “I have an understanding of what my voices are and where they come from and as I’ve been able to cope with them better…they’ve reduced then that’s made life a lot better…” (Payne et al., 2017, p. 211). Matching my own experience, as fellow voice hearers were able to talk about their experiences and gain an understanding of them, they felt more at ease and developed more control of life, emphasizing the need for patient-led support groups and other forms of care (Payne et al., 2017).

Sensory-Validating Care

My sensory-validating care techniques include five acts or tenets of providing care: supportive listening, reality affirmation, creative and strategic problem solving, skill-building including coping skills, and peer support (Knight, 2013). While I am putting forth this technique as a suggestion for care to be explored further, these acts of care have not been tested in conjunction with each other, although I provide evidence or testimonies supporting individual components. Furthermore, though the work I am building on comes from medical professionals, these are not medical treatments, nor am I a physician or a registered counsellor. I am simply someone who has been there and, most importantly, who knows what it feels like when no one works to understand what you are experiencing, making you effectively voiceless, even if you can feel that you are screaming.

Supportive Listening:

- Actively listening to what a psychotic individual is saying without trying to change their belief system (Knight, 2013)
- Providing empathy for their experiences. According to Naomi Feil, "empathy builds trust, reduces anxiety, and restores dignity" (Feil & Klerk-Rubin, 2022, p. 29)

Reality Affirmation:

- Accepting that a psychotic person's 'reality' is as real as anyone else's. When someone says that a psychotic person is not experiencing 'reality,' what they perhaps mean to say is that a psychotic person is not experiencing the same things as them. Our perspectives, and thus our realities, are limited, partial, and subjective (Haraway, 2013). What is 'real' is only our perception of what is going on in front of us, and thus, a psychotic person is not wrong about what is 'real' to them.
- Do not attempt to force a psychotic person to analyze or change behaviours, emotions, or thoughts. Do not assume that a psychotic person is not reacting appropriately to what they are experiencing. As explained in Naomi Feil's validation technique, asking 'why' questions or otherwise confronting a distressed person's behaviours or emotions can be

frustrating for them, especially if they are already not sure what is going on or what is happening to them (Feil & Klerk-Rubin, 2022).

- Using fact-based questions to orient yourself to the psychotic person's perspective – using who, what, when, where, and how questions to understand a psychotic person's 'reality.' A psychotic person might not know why they think or do something while disoriented or distressed—some coping mechanisms are as innate or intuitive as automatically turning your house key the right way when you put it into the lock. On the flip side, this does not mean that a psychotic person wants to keep everything they are thinking or experiencing to themselves. Someone who is willing to engage in their reality can be refreshing.
- Mirroring emotions and actions allows a friend or caregiver to enter a disoriented person's world better and shows them that they are not alone in how they feel or act (Feil & Klerk-Rubin, 2022).

Creative and Strategic Problem Solving:

- Helping the psychotic person to imagine opposite or alternative scenarios (Feil & Klerk-Rubin, 2022). This might lead to uncovering a pattern in which a psychotic person's most distressing thoughts, beliefs, or voices occur. For example, you can ask someone who believes aliens are after them, "Is there a time or day when the aliens do not show up? What are you doing then?" This can help to reveal particular coping strategies (Feil & Klerk-Rubin, 2022). For example, if the person never encounters the aliens when they are with someone else, a caregiver might help them develop a buddy system so that they are never or rarely alone.

- Using ambiguity to communicate with someone who is seemingly not making any sense (Feil & Klerk-Rubin, 2022). For example, if someone says, “These girls are poisoning me with trinkets through the radioactive stuff.” A friend or clinician could respond with broad, unspecific questions to gauge more information or to allow the individual to speak freely, such as, “Where do they do that?” (Feil & Klerk-Rubin, 2022). This gives psychotic individuals the freedom to communicate without feeling like they are being shut down by others who do not know how to communicate with them or who are too afraid to do so.
- Researching the types of beliefs or voices that a person is experiencing through books or websites to try and find coping mechanisms that will help a psychotic person (Knight, 2013). For example, carrying objects made of iron is a way to ward off aliens or faeries, according to spiritual folklore (Knight, 2013). Finding this information and presenting it to a psychotic person may give them a tool they can use to protect themselves from undesirable beliefs or voices.
- Developing reassuring statements specific to the psychotic individual's belief system. For example, “If you are being watched by the government, you have not done anything wrong” (Knight, 2013, pp. 26-27). This can help to turn the situation around, so it is no longer fear-inducing but rather mildly inconvenient.

Building Coping Skills and Other Skill-Building:

- Individuals with schizophrenia and other psychotic disorders may suffer from impaired cognitive and social skills (Kurtz, 2013, p. 64). Furthermore, “…no studies link a drug-induced reduction in symptoms with the ability to hold down a job, live independently and sustain interpersonal bond" (Kurtz, 2013, p. 64). Considering this, a therapeutic approach initially developed for brain injuries, known as cognitive remediation therapy, may be used to improve "…patients' ability to concentrate, remember, plan and solve problems, either by restoring skills through repetitive practice or by acquiring strategies for bypassing those deficits" (Kurtz, 2013, p. 65). This type of therapeutic approach might be best for psychotic individuals who would like psychological treatment of some kind, especially if medications have not worked for them.

- Anxiety management strategies can be adapted to work within a person's belief system (Knight, 2013).
- Engaging a psychotic person to learn more about their experience of voice-hearing or strong beliefs in order to come to terms with it. For example, a systematic method developed by Romme and Escher includes asking the voice hearer the following two questions: Who do the voices represent? What problems do the voices represent? (Romme, 2013a, p. 155). In my case, I often heard the voices of family members plotting against me. What this represents to me is an internal feeling that my family members never thought I was good enough at whatever I did, thus sabotaging my self-confidence and causing me great anxiety. While this might not seem like the truth from their perspectives, exploring these connections between my voices and my life story helps me to tether my voices back to the ground. Instead of floating above my head like large, looming ghosts peering down at me, they fizzle at my fingertips like little bursts of fear, but they are familiar to me now—knowable—and hold less power.

Peer Support:

- See the Hearing Voices Network section for information on the benefits and importance of peer support. See hearingvoicesnetworkontario.ca for my initiative to bring Hearing Voice Networks to Ontario, Canada, the province in which I reside.

Attrition

While modelling forms of alternative care may receive critique and backlash, especially from mental health care professionals, another model may receive even more so: the attrition model of psychiatry (Burstow, 2019). Succinctly explained by Bonnie Burstow, the attrition model of psychiatry assumes that ending psychiatry, or the ‘abolition’ of psychiatry, is a long and slow process, requiring sustained persistence and that some changes to the ‘system,’ which may seem positive, may actually be undermining the goal of abolition (Burstow, 2019). Furthermore, Burstow asks abolitionist activists to consider several key questions: do suggested movements or projects work towards the abolition of psychiatry, or do they actually widen psychiatry’s reach (Burstow, 2019)? Will they end up adding legitimacy to the current system, even in trying to end it (Burstow, 2019)?

Why end psychiatry? As I have demonstrated, there is a clear need for psychiatrists to market individuals as ill so as to maintain their own legitimacy. How do psychiatrists benefit from posing others as ill? For example, Jane Ussher writes of the DSM-5, the psychiatric diagnostic manual, “Some [DSM-5] panels appeared more closely linked with Big Pharma than others — notably the mood disorders and schizophrenia panels, where 100 percent of experts had pharmaceutical connections...” (Ussher, 2011, p. 61). Furthermore, pharmaceutical companies have a vested interest in ensuring that psychiatrists are prescribing their medications, as “Pharmaceutical companies are among the most profitable in the world — with global sales topping USD 400 billion in 2002…” (Ussher, 2011, p. 59). Additionally, in trying to legitimize themselves, psychiatrists must de-legitimize the views and opinions of their ‘patients,’ sometimes deeming them ‘incompetent’ for thinking or acting differently. As Ussher writes, “The fact that [people] reporting mental health problems are considered to be biased or subjective, yet researchers are not, illustrates the absence of reflexivity in positivist/realist research…” (Ussher, 2011, p. 56). Yet, there is a need for narrow, unreflective thinking in the field of mental ill-health, or else one begins listening to their ‘patients.’

Some ways I have embodied the goals of the attrition model of psychiatry are through using Mad language and shifting the discussion from that of psychotic ‘illness’ to emotional crisis or turmoil. Yet, one might argue that by still using the words ‘psychosis’ or ‘psychotic’ or ‘schizophrenic’ that I am still playing the game of illness-focused language. At the same time, I do not disagree that I have experienced an emotional crisis and using the word ‘psychosis’ is perhaps easiest because it denotes the specific kind of emotional crisis, but we need to pull the illness out of psychosis. One reason I use the word ‘psychotic’ for myself is as a reclamation and so that I can shift what it means to be psychotic. Poor insight is supposed to be one of the hallmark ‘symptoms’ of psychosis, for example, yet I would be hard-pressed to accept that I do not have insight about what has happened or still happens to me or that I am the only knowledgeable one. We are used to hailing psychiatrists as the be-all and end-all when it comes to mental health knowledge, and I have illustrated throughout this paper multiple ways in which psychiatrists have acted as anything but allies to Mad people.

Conclusion

In this paper, I have discussed the lived experiences of individuals who experience psychosis, including my own story using autotheory, and how these experiences are shaped not just by biology or pharmacology but by social and emotional processes. Furthermore, in exploring multiple case studies—spanning from the Civil Rights era to the last few years—I have denoted lives and stories that have been shifted by the actions, or lack of action, on the part of Western psychiatrists. In advocating for Mad people, I have shifted the discussion back, rejecting a language of illness or deviance and explaining how Mad or psychotic or unwell individuals react naturally to the weight of their circumstances. I have also put forth a model for the care of individuals with psychosis, primarily based on the work of Marius Romme, who founded the largely successful Hearing Voice Networks.

Finally, a few words to the Black people who are consistently and systemically mischaracterized. To the immigrants and refugees who have only what they carry. To the homeless folks who mumble to themselves. To the Indigenous peoples whose spirituality is misrepresented as delusion. To the substance users who hear and see things that they are not sure they should. To the adults experiencing paranoia who are trying to be good parents. To the children who are learning with time that they are different. To the ones who will never make it out of the hospital. To the ones who will never make it home. This was written with you in mind. May this community, Mad or ex-patient or otherwise, be home for you. May my words soften the edges of a world that has likely not been kind enough to you. May we find peace. May it fall like rain upon all of us, and may we know justice, ringing its righteous bells.

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