

MENTAL PATIENT

PSYCHIATRIC ETHICS FROM A PATIENT'S PERSPECTIVE



ABIGAIL GOSSELIN

Mental Patient

Basic Bioethics

Arthur Caplan, editor

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Mental Patient

Psychiatric Ethics from a Patient's Perspective

Abigail Gosselin

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To Rhea and Phoebe

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Introduction

When I was receiving treatment for psychosis a few years ago, I underwent a huge fissure in my identity and experience. Here I was, a middle-aged, heterosexual, married White woman with children, a philosophy professor used to directing students and working with colleagues, now in the most vulnerable position I could imagine. I had lost my mind, my sense of self, my identity, my ability to interact with others and respond to the world appropriately. I no longer felt like a professional; I no longer felt like a grown-up. I felt lost and confused in my psychosis, and I felt like a child on the receiving end of treatment from mental health professionals, obligated to obey (to comply with treatment) yet feeling irrationally defiant, stuck in my sickness. Doubtful my situation could ever improve, I was unsure if I even wanted to get better. To go from being a professional, grown woman in charge of many things to feeling like a lost and confused child victimized by psychosis and at the mercy of others was a seismic shift in how I experienced the world and how I understood myself.

Feeling lost and bewildered, I had difficulty relaying to others what I was experiencing. My psychiatrist and I were often at loggerheads due to miscommunication and misunderstanding. My family and friends could tell something was seriously wrong with me, but they struggled to understand, and I found it difficult to express myself accurately. Confused in my own mind, I struggled to articulate to myself what I was going through by writing about my experiences; immersed in the strangeness of my experience, I was able to chronicle my symptoms but unable to explain their significance. This difficulty came partly as a result of lacking a broader framework within which to understand my experience and partly as a result of being unable to think clearly within my psychosis. As months passed, and then

two years, my psychosis eventually receded, and I found it easier to think clearly and to read and write.

As reading and writing became easier, I did what good academics do: I tried to understand my experiences in academic terms. Immersing myself in various philosophical, psychological, and scientific literatures, I tried to understand how academics understood psychosis and recovery to see how this meshed with my own experience. The philosophical literature on hallucinations and delusions fascinated me; some of it gave me helpful new ways to understand my experience, while others of it seemed to be abstract theorizing with very little basis in reality. The scientific literature on effects of antipsychotic medication was educative and made me feel a little more reassured about the safety of my medication. The nursing literature on auditory hallucination simulations frustrated me, making assumptions about hallucinations that were narrow minded and problematic. The psychological literature on recovery from severe mental illness was illuminating and struck me as right on target.

The philosophy literature in general was rather limited. In the context of philosophy of psychiatry, I found that some philosophers seemed to have a good understanding of the experience of psychosis and the ways that psychosis constrains agency and autonomy, but others did not. While there is much written in scientific and psychological literatures on recovery (and much of it good), there is relatively little written in philosophy about the experience of recovery and what recovery requires, especially recovery from psychosis. What I thought was needed was a detailed understanding of the precise ways that psychosis can impair agency and autonomy and how this can make recovery so difficult. Many philosophers did not seem to understand the pull of psychosis, the way psychosis can feel like it has agency of its own and the way that this can hinder recovery. As a result, they did not have a clear understanding of how the quality of the therapeutic relationship is so central to recovery and how recovery requires engaging in epistemic and moral activities that increase agency and autonomy. In writing this book, I set out to articulate these themes as best as I could.

Equipped with academic frameworks with which to understand my experience, I also wanted to have an intelligible and respectable way to tell the mental health professionals with whom I worked what they were doing right and what they could do better. My experience with clinicians was mixed; at times, I felt deeply understood and respected by my clinicians,

and I felt that I could trust them to guide me well. At other times, I felt greatly misunderstood by and experienced condescension from my clinicians, and I did not believe they could help me out of my sickness at all. When I was in the throes of psychosis, I had some very frustrating experiences working with clinicians who did not understand psychosis (probably at least partly because they had little experience treating psychotic patients). I wanted to write about my experiences as a mental patient in order to be able to articulate to clinicians some aspects of psychotic experience and recovery that they didn't seem to understand. In particular, I wanted to explain why psychotic patients sometimes feel ambivalent about recovery and struggle to stay committed to recovery, hoping that with this knowledge clinicians could do a better job treating recalcitrant patients.

This book is written with two motivations in mind: to explain my experience of psychosis and recovery in philosophical terms and to make recommendations to clinicians about what they should do to help patients like myself in recovery. I want both academics and clinicians to rethink some of their previous suppositions about psychosis and recovery, and I want them to learn some aspects of what it can be like to suffer from psychosis and what it can be like to be a mental patient at the mercy of those professionals tasked with treating them. This way, clinicians can do a better job at treating psychotic patients, and academics can better understand a condition with which they usually have little personal experience. Philosophy provides useful tools and frameworks for understanding the nature of psychosis and recovery, which can be used to improve therapeutic relationships between clinicians and patients and provide direction for treating psychotic patients; but, in order to be useful, these must be grounded in real-life experience. In providing a firsthand perspective of recovery from psychosis, this book grounds the philosophical discussion of psychosis and recovery in real-life experiences for the benefit of clinicians and academics alike.

Patients' experience with mental disorders can vary considerably, even among patients who suffer from the same disorders; thus, my experience may not be applicable to all people who have severe mental illness, or even all people who suffer from psychosis. I am more privileged than many who suffer from severe mental illness, as I have a stable job, a spouse, and a home, and I have never been subject to violence, abuse, or traumatic coercion in mental health treatment. Partly because of my privileged background, I have had more positive experiences with the mental healthcare system than

negative experiences, which gives me more hope and optimism in the system and makes it easier for me to trust clinicians compared to many others with the same mental disorders. While my perspective is limited, and my experiences are particular to me, my experiences nonetheless probably share many similarities with those of many other patients and thus can be fruitful for understanding some aspects of psychosis and recovery, at least for some people. Throughout this book, I analyze my own experience in order to illustrate certain aspects of some people's experience with psychosis and recovery, especially in relation to agency and autonomy, situating my experience within the context of psychosis and recovery more generally.

This book is for anyone who wants to understand a perspective of what it is like to be working on recovering from psychosis and to be a mental patient being treated for psychosis. In using philosophical frameworks for thinking about psychosis and recovery, this book provides an academic examination of psychiatric ethics issues such as autonomy, paternalism, medicalization, trust, coercion, empathy, epistemic justice, and narrative approaches that arise in the process of recovering from psychosis. In connecting with personal experience of psychosis and recovery, this book grounds the academic discussion of psychiatric ethics issues in real-life experience to make it more relevant and less abstract. I explain some of the particular vulnerabilities that some patients experience due to their illness and to the way they are positioned as sick people needing treatment, and I highlight some of the particular difficulties that patients may experience with recovering from psychosis. In examining the patient experience, this book illuminates the complicated process of recovery from psychosis using philosophical frameworks from a patient perspective.

In this book, I explain one person's experience of what being psychotic is really like, showing how it can pull a person in and destroy their abilities to function in various life activities, to make choices that are truly their own, and to act with integrity. I also explain what one person's experience with recovery is like, demonstrating how much work recovery can involve and what kind of support a patient may need from mental health professionals. The book details some of the activities that a patient may need to do as they are working on their recovery in order to be successful, by practicing exercising their agency in various ways, with the support of clinicians who guide them to think more clearly and rationally and to value what is truly worth valuing.

In my experience, psychosis was personified: it had its own agency, autonomy, power, and persuasiveness, all of which overwhelmed the power that I had as an individual. Psychosis had the power to replace the values and goals that I had had before I was sick with values and goals of its own, supplanting my own vision of what a meaningful life consists of—formed through years of experience as a wife, mother, and professor—with its own view. It had the power to motivate me to adopt its vision of a meaningful life and to take the steps necessary to achieve this vision, despite the fact that this conception of a worthwhile life contradicted and thwarted my own view. This way of understanding psychosis as having power and agency of its own in framing what choices are available to a patient provides a unique perspective into what it can be like to have and to overcome psychosis.

From the vantage point of having overcome psychosis, with some distance between the time when I was psychotic and now in my present frame of mind, I can see that psychosis is not truly like a person and does not truly have agency of its own. But when I was in the midst of psychosis, it sure felt like psychosis had this power. Some of the way I talk about psychosis in this book assumes this personification and agency granted to psychosis because this is the only way I know how to convey what power it held over me.

Recovery from psychosis is often hard, harder than anyone who has not experienced it can know. In order to recover successfully, I needed treatment that would help me resist the vision, agency, autonomy, and persuasiveness of psychosis and help me reformulate a conception of a meaningful life independently of psychosis that could counter the goals dictated by psychosis. Medication helped me to perceive reality more accurately and to reduce the power of psychosis, while therapy helped give me the tools to reconceptualize what a worthwhile life consists of and to make choices and take actions that allowed me to pursue this more autonomous vision. Recovery was a struggle, however, because the psychosis wanted to keep me in its grip and prevented me from being able to accept treatment wholeheartedly. It took a lot of trust in my clinicians, in science, and in the promise of a better life for myself to be able to take my prescribed medication consistently and to do the work required in therapy. Through empathetic understanding, therapeutic alliance, and epistemic humility, the best clinicians I worked with helped me to deliberate more intentionally about what was important and about how to act on my values and achieve my goals. When clinicians empowered me to exercise my agency and to develop my

autonomy, they gave me the tools to confront my psychosis and lessen its power over me.

The book proceeds as follows. Chapter 1 introduces the concept of a “mental patient,” explaining what psychosis is and how it impairs epistemic and moral agency. Chapter 2 analyzes the way that psychosis impairs autonomy and autonomous choice. Examining the way psychotic experience is medicalized, chapter 3 explores what it is to be a patient receiving mental healthcare treatment from clinicians. Following this, chapters 4 and 5 examine two crucial aspects of a productive therapeutic relationship: trust, both the patient’s trust in the clinician and the clinician’s trust in the patient, and empathy, namely the empathetic understanding a clinician must have of their patient’s experiences and perspective. The last three chapters explore three different activities that patients need to engage in as they work toward recovery in order to increase their agency and autonomy: giving testimony that is taken up by clinicians appropriately; making meaning of their experience by constructing a personal narrative about it and situating it within a larger framework of meaning; and making choices, especially choices to engage in treatment, but also choices to show up and participate in life activities more generally.

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