

Living with the Pharmakon: A Call for Futurity

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Abstract

This perspectives piece explores the tensions between the toxicity of psychoactive medications and lack of access to quality treatment and specialist nephrology care for people with, what has been defined by the medical community as, bipolar disorder and schizophrenia. What becomes of livability if the system of medicine creates harm in supposed remedy while refusing remedy and creating harm? This essay calls out the limits this contradiction places on the possibilities for life, and it is concerned with what kinds of futures materialize in living with the pharmakon.

Keywords

futurity, pharmakon, psychoactive, toxicity, transplant

Introduction

In this perspectives piece, I am interested in the tensions between the toxicity of psychoactive medications and lack of access to quality treatment and specialist nephrology care for people with, what has been defined by the medical community as, bipolar disorder and schizophrenia. I question what becomes of livability if the system of medicine creates harm in supposed remedy while refusing remedy and creating harm. I call out the limits this contradiction places on the possibilities for life, and I am concerned with what kinds of futures materialize in living with psychoactive medications, or what I collectively call the pharmakon. My motivation for this writing is personal as much as it is scholarly—I am what I would describe as a feminist technoscience scholar living with a bipolar disorder diagnosis, the drugs prescribed to remedy my symptoms, and the harmful side effects of these medications. I acknowledge my limited perspective from the outset—I am not a transplant researcher nor a clinician—which prevents

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me from fully addressing the complexities and intricacies of transplant medicine as they sit in tension with the toxicity of psychoactive medications. My aim is to call for those deeply engaged with this work to take up lines of inquiry and action.

My initial interest in transplant medicine stems from my stint as a histocompatibility and immunogenetics laboratory technician. In the lab, patients were represented as disembodied vials of blood, buffy coats of white blood cells, and extracted fragments of DNA. And for many years, because of my narrow science education, I too often viewed science, technology, medicine, biology, bodies, and matter through this decontextualized perspective. But over time I began to see not through the lens of separation and fragmentation. I now understand there is potential for harm in leaning too heavily into a decontextualized, abstract engagement with materiality without attention to a situated materialist account of the world that is cognizant of matter across scales (Roy and Subramaniam 2016)—from the modulation of multi-neurotransmitter systems through psychoactive cocktails to the management of exclusive transplant waiting lists through psychosocial evaluations. I have not thought about transplant medicine in my scholarly work since my time in the lab until I viewed this call for papers. I have, however, thought about it quite a bit in my personal life, not because of any present medical need but rather because of my fixation on my future as it is lived entangled with the pharmakon, and this is my initial attempt to bring the two into conversation.

Living with the Pharmakon

Teena Gabrielson writes, “Inherently slippery, the polysemous root of the adjective ‘toxic,’ *pharmakon*, refers not only to poison, or philter, but also to remedy, medicine, drug” (2016, 173). Pharmakon signifies in seemingly conflicting directions, and, yet, despite binary logic that aims to break the stitching that binds them, the paradoxical characteristics cannot be disentangled. In Emily Martin’s *Bipolar Expeditions*, the accounts of psychoactive medications she collected “are permeated with ambivalence—simultaneous and contradictory feelings of attraction and repulsion...The drugs help me, they hurt me; they ease one kind of pain and intensify another; and they take away one painful symptom but add a new one” (2007, 171). Living with the pharmakon invokes a never-ending series of trade-offs; I urge you to grapple with this knotty reality. Asha Persson adds the productive potential of the pharmakon in her analysis of antiretroviral therapy—the “capacity to reconfigure bodies and diseases in multiple, unpredictable ways” (2004, 46). This is the volatile work of psychoactive drugs with which I am particularly concerned and believe others should be as well.

I have succumbed to taking psychoactive medications as necessary for my survival, despite their well-established toxic characteristics and yet all that is not known about their mechanism of action in my body, though this is difficult to accept and admit. Making decisions around pharmaceutical treatment (or the lack

of pharmaceutical treatment), if even given the option, is, and can perhaps only ever be, fraught and entails negotiating a range of primary and what are considered side effects. Despite the availability of newer—and supposedly less toxic while often more expensive—psychoactive drugs, side effects continue to complicate psychopharmacological treatment of affective and psychotic symptoms. Side effects of these medications are often silenced or pushed aside out of fear of noncompliance. Alternatively, side effects are used as justification for discrediting their use. Against either of these stances, I advocate for engagement with the complexities and contradictions inherent in pharmaceuticals rather than moving directly to an anti-pharmaceutical position despite my awareness that this might be an undesirable request.

Lithium, a common treatment for bipolar disorder, may cause “hypothyroidism, hyperparathyroidism, nephrogenic diabetes insipidus, and decline in renal function” (Van Alphen et al. 2021, 1). In their international review, Claire Carswell et al. (2023) found that there is increased risk of chronic kidney disease in those who are diagnosed with bipolar disorder, and Clodagh Cogley et al. (2022) explain that these higher incidences can be partially explained by known factors, such as the use of lithium. From an intersectional perspective, chronic kidney disease is more common in women, and this has been shown in those who take lithium specifically, with younger women at a particular risk (Hayes et al. 2021; Shine et al. 2015). At issue is the often long-term use of lithium. Research shows that lithium “has the potential to cause end-stage kidney disease, albeit over a prolonged period...with some studies suggesting that a period of around 27 years may be required to see significant nephrotoxicity occur” (Davis, Desmond, and Berk 2018, 1). End-stage kidney disease is reportedly relatively rare in people taking lithium likely due to close renal monitoring with a focus on serum lithium levels, but there have been cases of lithium-induced end-stage kidney disease (Beasley, Larson, and Garcia-Pittman 2018; Kerckhoffs, Hartong, and Grootens 2018; Van Alphen et al. 2021). However, some uncertainty remains about the incidence of renal failure in people taking lithium, and data about the prevalence of lithium-induced end-stage kidney disease are sparse (Van Alphen et al. 2021).

A surprising finding from my review of relevant research was the relationship between psychoactive medications other than lithium and the risk of chronic kidney disease. Potential adverse effects of antipsychotics, particularly the second-generation antipsychotics, include but are not limited to sedation, akathisia (psychomotor restlessness), sexual dysfunction, tardive dyskinesia (repetitive, involuntary muscle movements), myocarditis (inflammation of the heart muscle), risk of sudden cardiac death, neuroleptic malignant syndrome, and metabolic syndrome (involving weight gain, high blood pressure, high blood sugar, high triglycerides, and low HDL cholesterol) potentially leading to diabetes and cardiovascular disease with studies also linking them to an increased risk of chronic kidney disease (Carswell et al. 2023; Damba et al. 2022; De Hert et al.

2012; Stroup and Gray 2018). Diabetes and hypertension are the most common causes of chronic kidney disease generally, “conditions that are significantly more prevalent among people with [bipolar disorder and schizophrenia], in part because of the side effects of antipsychotic medication” (Carswell et al. 2023, 1520). Mikkel Højlund et al. explain that rather than second-generation antipsychotics directly increasing the risk of chronic kidney disease, they “contribute to metabolic disturbances, which in the end result in kidney damage” (2020, 6). And the mechanism responsible for these metabolic changes is not fully understood and may be multifactorial (DeJongh 2021, 311). While I didn’t find any mention of antipsychotic-induced end-stage kidney disease in my research as I did for lithium, I believe these drugs warrant monitoring for their potential impact on kidney health.

A Call for Futurity

Carswell et al. write, “While people who have [what is described as severe mental illness, such as bipolar disorder and schizophrenia] are less likely to reach kidney failure, this is most likely a result of them dying too early for their disease to progress” (2023, 1544). Given the phenomenon of the mortality gap of people diagnosed with bipolar disorder and schizophrenia caused, in significant part, by long-term physical health conditions, I think a lot about life, living, dying, and death. Alison Kafer writes, “Ideas about disability and disabled minds/bodies animate many of our collective evocations of the future; in these imaginings, disability too often serves as the agreed-upon limit of our projected futures” (2023, 27). As with Kafer, I imagine futurity otherwise, but I am not speaking here about the curative imaginary that cannot imagine a future beyond medical intervention and its concern with compulsory able-bodiedness (27). And yet, I do want to focus on medical intervention—access to quality medical intervention for those who desire it (even if ambivalently so). I acknowledge that while some have fought for a reduction in the role of doctors and other medical clinicians in their lives, “feminist and antiracist health activists have historically had to fight for, first, access to medical care,...and, second, for improved quality of care, that is, health care free from racial, gendered, sexual, and (dis)ability discrimination” (Schalk and Kim 2020, 45–46). While this mortality gap can be partially attributed to higher rates of comorbidities, there is evidence that unequal access to health care is critical to this disparity (Cogley et al. 2022).

I am writing in response to Kafer’s blunt assessment that “disabled people are continually being written out of the future,” and, she cautions, “This erasure is not mere metaphor” (2013, 46). Carswell et al. (2023) found that though there is increased risk of chronic kidney disease, those who are diagnosed with severe mental illness are less likely to receive specialist nephrology care, less likely to be evaluated for a kidney transplant, less likely to be on the register to receive a kidney transplant, and less likely to receive a kidney transplant, suggesting significant inequalities in kidney care. This reality exists despite studies showing

“similar outcomes following transplantation, with no evidence of increased rejection rates, graft loss, or mortality” (Carswell et al. 2023, 1544). Equitable access to transplantation is especially important for people diagnosed with bipolar disorder, “as for a significant proportion of these patients, the primary, and potentially avoidable, cause of [end-stage kidney disease] is long-term lithium treatment” (Butler et al. 2017, 73). That there is potential for harm in the remedy of psychoactive medications is troubling, but that the profoundly uneven medical system could exert another harm by withholding remedy is particularly vexing given that “the presence of a severe mental illness has been considered a relative or even absolute contraindication by some” (Cogley et al. 2022, 1415). Exclusion from transplant programs has previously been due to concerns regarding adherence to post-transplant regimens, cognitive and emotional capability, potential interactions between immunosuppressant and psychoactive drugs, exacerbation of psychiatric symptoms, and inadequate social support with limited data to support these concerns (Cogley et al. 2022). This essay was prompted by Katherine Cahn-Fuller and Brendan Parent’s (2017) call for justice for people denied transplantation based on a psychiatric diagnosis across medical specialties. Cahn-Fuller and Parent (2017) were concerned with transplant eligibility criteria as exclusionary, but it seems that while this remains an important area of focus given the continued inconsistent eligibility guidelines across transplant centers in the United States, the relevant factors of health inequities are far more pervasive than this alone and are present across levels of (supposed) care.

The issue of medicalization with psychoactive drugs and the potential adverse impact on the body, particularly the kidneys, sits in tension with under-medicalization and a lack of access to quality treatment and specialist nephrology care. I question again—What becomes of livability if the system of medicine creates harm in supposed remedy while refusing remedy and creating harm? In contemplating what of a situated, intersectional account of life with the pharmakon, I return to the need for understanding across scales, which is why I believe researchers across disciplines and clinicians across specialties must engage with each other—we need a present and future of cross-disciplinary solidarities to provide the quality care that is desperately needed. This collaboration requires a shared understanding of disability that goes beyond the medical model, though I am not arguing for a simple rejection of medical intervention but rather a complex interrogation of the medical assemblage. I encourage researchers and clinicians “to not only (re)think how bodies and...drugs come together, but also how side effects become actualized in a given assemblage of bodies, drugs, objects, people, relations, events, discourses, practices, and institutions” (Gagnon and Holmes 2016, 253). What discursive practices are at play in the decisions regarding the use of psychoactive drugs, which medications, and at what doses? And what of the power dynamics involved in these decisions? What of monitoring and treatment for adverse effects and

perhaps inequitable monitoring and treatment across race, gender, class, nation, and other differences? For whom, at what point, and for how long are hemodialysis machines necessary? Who is and who should be eligible for a kidney transplant and under what conditions? What is and what should be the relationship amongst patients, psychiatric prescribers, nephrologists, and other clinicians? How can we create a more accessible, just, and interconnected medical system for people living with bipolar disorder and schizophrenia diagnoses that provides holistic care for bodyminds? I call for situating psychoactive drugs in the context of the institutional practices and power relations of medicine and the lived realities of the people entangled in these assemblages, as one focal point of which there should be many, to open possibilities for life, living, and the materialization of more livable futures.

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Author Bio

Stephanie L. Hudson is a scholar working across disciplines in biosciences and feminist studies.