

Psychiatric Medication Withdrawal: Survivor Perspectives and Clinical Practice

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Abstract

As patient/survivor movements continue to challenge reductionist biological views mental health and psychosis, there is rising skepticism toward psychiatric medications and growing interest in withdrawal and alternatives. This new perspective also calls for a rethinking of reductionist assumptions about psychiatric medications themselves. General medical patient experience with collaborative decision making for other conditions has broad implications for psychiatric drug withdrawal, and by recognizing psychiatric medications as psychoactive substances, addiction science also suggests a central role for social context and therapeutic common factors in medication withdrawal response. New understandings of madness and medications support an emerging reconsideration of what constitutes the very definition of “health,” where measuring the absence of disease symptoms gives way to a systems-based focus on self-management, social relationships, and adaptability.

Keywords

collaboration, DSM, mental disorder, psychiatric drugs, psychiatry, psychotherapy, qualitative research, schizophrenia, therapeutic relationship, psychosis

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Emerging research urges greater caution in psychiatric medication treatment, including for psychotic disorders where medications have been considered indispensable (Murray et al., 2016). Adverse effects may eclipse the original condition (Moncrieff, 2006), while iatrogenic harm (Crace, Götzsche, & Young, 2015) is for many an obstacle to health (Starfield, 2000). Patients often try to discontinue psychiatric medications despite strong resistance or lack of support, and many report severe withdrawal effects (Salomon, Hamilton, & Elsom, 2014). However, those living well after coming off medications (Harrow, Jobe, & Faull, 2012; Larsen-Barr, 2016), or coping without ever beginning medications (Seikkula, Alakare, & Aaltonen, 2011), are gaining visibility, even diagnosed with psychotic conditions such as schizophrenia and bipolar disorder they were told required lifelong medication.

Reconsidering medication efficacy parallels rethinking madness itself (British Psychological Society, 2016). Are mental illness and psychosis brain disorders as claimed? And what of patients who took medications under assumptions that are now questioned? As a result of this growing skepticism, calls are emerging for more research, especially to fill the gap of investigation into medication withdrawal (Larsen-Barr, 2016).

From my vantage point, as a former psychosis patient and today as a therapist, support group facilitator, trainer, and PhD researcher, I see an additional question: Can we rethink psychiatric medications and withdrawal? Neurobiological assumptions have constrained how we understand madness; do these same assumptions also limit our understanding of the medications taken to treat it? (Hall, 2007).

Medical Decision Making: A Changing Relationship

Collaboration is taking place throughout medical decision making and research (deBronkart, 2015). Patients, families, and advocates are actively involved in efforts to find better care for conditions no longer considered exclusive expert purview, including spinal cord injury, neuromuscular diseases, renal failure, asthma, chronic obstructive pulmonary disease, burn care, diabetes, and intellectual disabilities (Abma & Broerse, 2010). Crowdsourced knowledge, in the era of Wikipedia and online discussion forums, is transforming science. And this collaboration not only leverages distributed minds to work together but also improves patient satisfaction and clinical outcomes (Joosten et al., 2008; Shay & Lafata, 2015).

However, collaboration around psychiatric conditions has trailed behind this general trend (Hamann, Leucht, & Kissling, 2003). The founding of the Insane Liberation Front and Scottish Union of Mental Patients, the underground publication of “Dr. Caligari’s Psychiatric Drugs,” and other milestones

of the 1970s patients' movement are all sustained in today's continuing calls for a survivor voice in medication treatment practice (Hall, 2016). Psychiatric decision making certainly can have life or death implications—but so do end-of-life care, surgeries that risk brain injury or paralysis, and terminal illness. The personal gravity of medical decision making is precisely what warrants greater collaboration, not less. When Apple founder Steve Jobs chose to delay recommended treatment for pancreatic cancer, possibly costing him his life, it was understood to be his decision to make. To be fully human means being recognized as having equal rights to choose medical risk.

Shared Withdrawal Lessons

In this era of aggressive pharmaceutical marketing, patient collaboration is already addressing the wide concerns about adverse drug effects throughout medicine—collaboration that encompasses decisions on drug discontinuation. Thriving online discussions address drug withdrawal for epilepsy, chronic pain, type 2 diabetes, asthma, hypertension, high cholesterol, hormone replacement, and many other conditions. Where psychiatric patients have encountered physician resistance around the decisions affecting them, they've taken their own initiative on withdrawal (Hall, 2007), as well as inspired a burgeoning survivor research literature. Can psychiatry learn lessons from other areas of medical collaboration?

While diabetes is not depression or psychosis, there remains a human being at the center seeking wellness. For all the leading medical conditions, lifestyle changes and patient involvement in care are vital aspects of recovery. What have been some common experiences around withdrawal from corticosteroids for asthma, beta blockers and ACE (angiotensin-converting enzyme) inhibitors for hypertension, statins for high cholesterol, progesterone hormone therapy for menopause, opioids for pain management, sulfonylureas for type 2 diabetes, and antiepileptic drugs for seizures? They include

Diversity and unpredictability: The same condition and medication will be different across patients. Searching for the “right thing to do” is always a pitfall, as few decisions ensure results; all carry risk, and different physicians have different opinions (Bola & Mosher, 2002; Liu et al., 2013).

Tailoring decisions to individual needs: “One size does not fit all” is a frequent refrain, as each person's unique life conditions will indicate a distinct relation to treatment (Specchio & Beghi, 2004). Diverse lifestyle changes are often at the center of withdrawal approaches.

Importance of gradual withdrawal: While abrupt withdrawal can sometimes be indicated, “tapering” is a theme for many drugs across

conditions, to give opportunity for body and person to readapt to a pre-medication state and avoid rapid discontinuation effects (Hixson, 2010). *Paradox of making conditions worse:* Antiepilepsy drugs have been shown to cause worsened seizures over time (Perucca, Gram, Avanzini, & Dulac, 1998), paralleling concerns that antipsychotics can worsen psychosis (Murray et al., 2016). The experience with antibiotics is instructive: Pharmacology now suggests a broad pattern where drug treatments in general risk exacerbating the conditions they were prescribed to treat (Reidenberg, 2011).

Informed risk-benefit consideration: Much patient decision making focuses not on certainty but on risks and benefits to be calculated into a personal choice (Czyżewska-Majchrzak, Grzelak, Kramkowska, Czyżewska, & Witmanowski, 2014).

Dignity of risk and autonomy of the patient: Patients are free to assume risk, even where there is disagreement, such as where discontinuing antiepilepsy drugs may cause a return of seizures (Hixson, 2010).

Rise of integrative and holistic medicine: Even if it might be “just” faith, placebo, or expectation, physicians are accommodating patient interest in integrative treatments where it strengthens the clinical relationship, motivates change, and improves patient agency (Dobos et al., 2012).

These considerations are shared by patient survivor movement approaches to psychiatric drug withdrawal (Hall, 2007).

Psychosis Treatments or Psychoactive Substances?

With no biological markers or disease-specific pharmacological action, psychiatric medications are best understood as *psychoactive substances*. Effects are individual and felt by anyone taking the substance (not just by one with a presumed disease). All psychoactives, whether alcohol or caffeine, Stelazine or Xanax, alter consciousness through changes to the brain and neurotransmitters, as well as expectation, placebo, and nocebo effects. Psychoactives are desirable or not depending on the person (Moncrieff & Cohen, 2009). They can create dependency similar to, and sometimes no different from, recreational substances. Though social values are reversed—we encourage patients to remain medication compliant while urging recreational drug users to quit—we can still ask, based on their similarities as psychoactives, what research on substances and addiction has to teach us about psychiatric drug withdrawal.

Despite decades of brain science and other research, there is no consensus on a best practice addiction treatment protocol (National Institute on Drug

Abuse, 2017). Patient diversity prevails, and we can therefore expect a proliferation of effective psychiatric medication discontinuation protocols, each with their adherents and detractors, but no winner for a one-size-fits-all. While the duration and degree of substance use suggests *general* implications for the difficulty of withdrawal, and gradual withdrawal does *seem* best for many drugs, even this is not absolute.

The War on Drugs exaggerated the power of substances; has the era of Big Pharma exaggerated the power of psychiatric medications? Illicit drugs such as cocaine and opiates, we are told, presumably have such a formidable addictive attraction to the brain that experimental mice will prefer the substance to food and water—to the point of death. But are drugs *themselves* really this diabolically powerful? Researcher Bruce Alexander manipulated not drug dosage or brain chemistry but nonpharmacological, environmental factors in experimental rats exposed to morphine. Alexander replaced confinement, isolation, food scarcity, and environmental stress with social connection, physical freedom, and resource abundance. Rats not only lost interest in the morphine but also still preferred food and water even when forced into morphine dependence. When nondrug, environmental, and social factors were more favorable, even previously addicted rats elected to endure withdrawal effects rather than take a readily available drug they were addicted to (Alexander, 2008).

Studies on psychoactive drug withdrawal similarly illustrate how substance exposure and dosage alone are not predictive of withdrawal effects. Subjects addicted to heroin or nicotine will demonstrate physiological withdrawal just from being told that their dosage is reduced, even if the dosage they take is actually the same; conversely, subjects will exhibit no withdrawal when told that dosage is the same when in fact it is reduced. U.S. soldiers in the Vietnam War who used heroin heavily mostly stopped on returning home, disproving fears of an addiction epidemic; and hospital patients heavily saturated with morphine do not generally demonstrate addiction on leaving. Neuroscientist Carl Hart confounded the presumed control an addictive substance itself has on the brain by showing that complete abrupt withdrawal in cocaine addicts was possible simply by manipulating a single, nonpharmacological or biological variable: paying them cash to quit (DeGrandpre, 2006; Hart, 2013).

Instead of a disease model that places centrality on drug properties, dosage, and neurochemistry, many addiction researchers propose an “adaptation” model that sees drug dependence as *a social situation in a life context* (Hart, Csete, & Habibi, 2014). Disability advocates have also shifted away from a medical model of physical difference to a social model that focuses on rights advocacy to change how differences are responded to and supported in

the society. As the psychiatric survivor movement challenges the reductionist biological view of human distress, it also needs a new model of psychiatric medications and withdrawal. Psychoactive drug discontinuation is a life change process and not reducible to a neurochemical event (Hart, 2013).

Social and situational factors are most evident in psychoactive substances and mental health, but the power of the mind is such that they shape drug use for all physical conditions as well. Drug efficacy throughout medicine is being rethought in light of placebo, nocebo, and expectation effects (Brunoni, Lopes, Kaptchuk, & Fregni, 2009), with growing recognition that a patient's life context, including culturally bound narratives of the self, plays a key role. The reported effect sizes and patient relevance in clinical trials for many common medications are poorly understood, calling into question the generalizability of clinical trial results for practical treatment and patients' daily lives. Researchers in one meta-analysis, which included psychiatric, cardiovascular, and other leading medicines, point to a widespread "cognitive bias" in prescription practices. "Doctors may believe that all patients respond to drugs and none to placebo, but neither statement is true because there is no ideal drug and many disorders remit spontaneously due to their natural course. Our preference for black or white over shades of grey is convenient but it can offer only a 'false clarity'" (Leucht, Helfer, Gartlehner, & Davis, 2015, p. 253).

What Helps? Common Factors

Asking "What treatment works best for psychiatric medication withdrawal?" confronts this general difficulty: With few exceptions, it is *common factors*, not treatment methodology, that account for psychotherapy efficacy, as shown in meta-analysis (looking at PTSD [posttraumatic stress disorder] treatment, ADHD [attention-deficit hyperactivity disorder], anxiety, depression, and others). The quality of the relationship, the confidence of the provider, and the capacity for patient feedback are common factors across methods and predict outcomes among all techniques. As a diversity of modalities—peer support, CBT [cognitive behavioral therapy], 12 steps [of Alcoholics Anonymous], neurofeedback, or others—become recommended for psychiatric drug withdrawal, we can expect outcomes to follow a similar pattern around these common factors rather than preferring one modality over another (Miller, 2009).

A New Understanding of Health

Psychiatric drug discontinuation is further complicated by the culturally bound nature of symptoms. Signs of disease in one culture aren't signs of disease in another, and individuals and their social context have different responses to

troubling and unusual experiences and different degrees of tolerance of discomfort (van Os, 2003). One person lives with hearing voices as a spiritual experience, whereas another is frightened into isolation; one accepts periods of suicidal despair as part of an existential worldview, whereas another does not; one person navigates mania through sleep and lifestyle changes, whereas another takes lithium (British Psychological Society, 2016). The destiny of an individual is always at least partly up to oneself to change: each person will be different, and no clinical standard of “success” can be generalized for everyone’s mental health. Likewise, relapse and disease recurrence are relative to individual experience and definition. As in epilepsy drug research, where patients may choose to risk seizure recurrence in light of many considerations around withdrawal, some patients will choose to risk “madness” in their decision to come off psychiatric drugs.

Psychiatric drug withdrawal therefore supports growing interest in a reconsideration of “health” itself. The prevailing understanding has been health as the absence of symptoms of disease,

the requirement for complete health “would leave most of us unhealthy most of the time.” . . . It therefore supports the tendencies of the medical technology and drug industries, in association with professional organisations, to redefine diseases, expanding the scope of the healthcare system. (Huber et al., 2011, p. 235).

The new view of health now emerging across disciplines places social context at the forefront:

. . . environmental scientists describe the health of the earth as the capacity of a complex system to maintain a stable environment within a relatively narrow range, we propose the formulation of health as the ability to adapt and to self manage... a more dynamic [formulation] based the resiliency or capacity to cope and maintain and restore one’s integrity, equilibrium, and sense of wellbeing (Huber et al., 2011, p. 237).

Conclusion

All oppressed groups confront legacies of scientific and medical research that endorses and legitimizes their oppression through claims of biological abnormality and inferiority. Patients who have survived hospitalization and medicalization mistreatment are following a path parallel with other social movements, challenging institutionalized medical knowledge and advancing community self-knowledge. As psychiatric medication discontinuation becomes more embraced in clinical practice, it will take the continued work of social movements to ensure that the voice of psychiatric patients is at the

center of new initiatives, including new agendas for research into drug withdrawal.

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