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Commentary

“I’m pretty sure it’s either food poisoning or Covid-19”: Lived experience versus medical knowledge in diagnosing substance use problems

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ARTICLE INFO

Keywords:

Withdrawal
 Methadone maintenance treatment (MMT)
 Benzodiazepines
 Harm reduction
 Stigma
 Addiction medicine

ABSTRACT

People who use drugs, or who have in the past, often report that doctors and/or treatment providers devalue, or are unwilling to believe their claims in regards to substance use issues, in particular the presence and severity of withdrawal. In the case of benzodiazepine withdrawal this can not only lead to significant discomfort, frustration, and trauma for patients, but can lead to serious medical problems. This commentary uses the authors’ recent first-person experience with a disbelieving doctor in order to illustrate the lack of value often given to the claims and narratives of people with lived substance use experience. I outline some of the potential problems with this approach, including the effects on patients themselves and the loss of an important source of evidence-based knowledge. It also discusses potential risks associated with the recent increase in benzodiazepine prescription due to Covid-19 and offers suggestions for improving treatment outcomes.

Introduction

I spent the majority of last week (at the time of this writing) fighting a minute-by-minute battle not to jump from the fire escape of my 4th story apartment in Queens, New York City. I wasn’t sure if the fall would kill me or just put me into some kind of a coma where maybe the doctors could take care of my problems while I was unconscious.

I knew from years of experience using drugs that I was suffering the effects of benzodiazepine withdrawal and needed to be stabilized and then slowly tapered off of them. However, I was unable to do so at first because my prescribing doctor – who also happens to be my methadone maintenance provider – did not believe that it was withdrawal that I was experiencing. Despite my insistence that I had been in withdrawal many times and knew what it felt like (as well as the fact that it began when I stopped taking Xanax), after consulting with a colleague he told me that I had not been taking them for long enough or in high enough doses to cause withdrawal. Rather, he was “pretty sure that it’s either food poisoning or Covid-19”.

Although I was finally able to convince him that my symptoms were in fact, the result of benzodiazepine withdrawal, it was only possible by citing research and then reaching out to non-drug-using scholars who could back up my claims and whose opinions he was less willing to discount. Had I not been a Ph.D. who studies substance use, with access to specific knowledge and resources – a privilege the vast number of people using benzodiazepines do not have – things could have turned out much worse.

My experience underscores how the social and cultural capital I have from academic participation is valued by medical providers in ways that

lived experience is not. Because of my academic status. I was able to advocate for myself and obtain a desirable outcome whereas without it, I likely would not have. This is true despite the fact that my claims were based on knowledge gained through lived experience rather than academic study.

Thus, while this event was a highly traumatic and un-necessary experience for me, it also demonstrates how little value medical professionals often place on voices and lived experience of people who use drugs (PWUD). Although research shows that this approach can lead to a lack of trust of medical providers, reduced willingness to utilize medical services, and negative healthcare outcomes, it remains all too common within medical settings (Meyerson et al., 2021; Nyblade, 2009; Ahern, Stuber, & Galea, 2007; Ford et al., 2004). Moreover, since several studies have shown a marked increase in anxiety, insomnia, and stress since the advent of Covid-19 and co-occurring political instability, benzodiazepines, antidepressants, and other dependence/withdrawal producing drugs may be prescribed at increasing rates, oftentimes to individuals with little or no experience in their characteristics or proper use (Agrawal, 2020; Chiappini, Guirguis, John, Corkery, & Schifano, 2020; Honig, 2021). An early analysis shows that between February 16, 2020 and March 15, 2020, the number of prescriptions filled per week for antidepressant, anti-anxiety and anti-insomnia medications increased by 21% (Express Scripts, 2020). Thus, upon future discontinuation of these substances, many people are likely to find themselves in the throes of withdrawal – a truly horrifying, disorienting, and potentially dangerous experience – without any frame of reference to understand what’s happening to them, and potentially receiving misinformation from the one source they are told to rely upon.

In response, this paper argues that PWUD’s experiences, and lived experience generally, should be given far more weight in treatment settings, particularly when dealing with highly specific, phenomenological

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experiences, like withdrawal, that the physician has never personally experienced.

Making the case for experiential knowledge

The lack of credence given to experiential knowledge is largely a product of Western medicine's basis in notions of objective, universal knowledge that is seen to be solely in the hands of "experts" (Gordon, 1988; Lang, 2011; Lupton, 2000). This view positions the physician/patient relationship as a top-down arrangement whereby an expert imparts objectively true knowledge to the recipient layperson patient.

Although medicalization and science studies scholars, often working from Foucauldian and/or constructionist positions, have deconstructed this model, pointing out that medical knowledge, like all knowledge, is situated within a specific socio-cultural and historical worldview, it remains dominant both culturally and within the institutions where medical personnel are trained (Conrad, 1992; Foucault, 1988; Good, 1993; Lang, 2011; Vrecko, 2010). In this case, medical practitioners today learn about substance use primarily through biological and genetically-focused theories that position problematic substance use as a disease and PWUD as "addicts", innately prone to lying and other misbehavior (Volkow & Li, 2005; Vrecko, 2010). Although research on the etiology of problematic substance use is highly contested and scholars have pointed out that addiction-as-disease narratives pathologize substance use and serve an ideological foundation for policies that criminalize PWUD (Reinarman, 2005; Vrecko, 2010), because of their institutional dominance, physicians are unlikely to learn anything outside of that perspective (Frank, 2018; Fraser, Moore, & Keane, 2014; Lewis, 2018; Reinarman, 2005). As a result, it becomes baked into the ways that medical practitioners conceptualize drug use and relate to people who use them, ultimately justifying the kind of paternalistic attitude physicians all-too-often adopt towards their patients who use drugs.

The situation is further complicated by the overall lack of knowledge among many physicians regarding how to properly identify and manage withdrawal (Brett & Murnion, 2015; Groot & Van Os, 2020; Lader, 2011). As Cohen & Recalt describe in their call for a paradigm shift in how withdrawal is studied, withdrawal been neglected by mainstream psychiatry and consequently it is not well understood (2020). They point out that "[N]o consensus definition of the physiological and psychological phenomena that may follow dose-reducing or stopping prescribed psychotropics has emerged, excepting those in successive editions of the Diagnostic and Statistical Manual of Mental Disorders." (2020). Similarly, a 1997 survey sent to UK psychiatrists and general practitioners found that only 20% of psychiatrists and 17% of GPs always caution patients about the possibility of discontinuations events (Young & Currie, 1997). This is particularly troubling in light of the recognized dangers of withdrawal which for some drugs, like benzodiazepines, includes risk of Grand Mal Seizures and death as well as an inability for patients to effectively discontinue medication regimens (Fialip et al., 1987; Groot & Van Os, 2020; Hauser, Devinsky, De Bellis, Theodore, & Post, 1989).

Scholars have placed some of the responsibility on addiction studies over-reliance on Randomized Controlled Trials (RCTs) which they argue has largely replaced direct observation of patients' experiences (Deaton & Cartwright, 2018; Honig, 2021). Although RCTs – which are seen to eliminate bias through randomized assignment of study participants to separate groups who are then exposed to different circumstances and observed – are often touted as the pinnacle of evidence-based data collection, their use of pre-determined conceptual categories, situated within a particular worldview, creates its own form of bias. As Deaton & Cartwright argued in a 2018 critique of RCTs, such methods were "not blinded nor sufficiently controlled for other sources of bias, and indeed many cannot be" (2018).

I would also argue that commonly used metrics, such as the Clinical Opiate Withdrawal Scale (COWS) scale, or worse, the ubiquitous

comparisons to the flu, do not capture the lived experience of withdrawal (Wesson, 2003). First of all, such measures do not account for the differences between withdrawal from different substances. Moreover, they also rely on characterizing withdrawal as a combination of symptoms, and thus, completely miss the larger affective experience. In particular, they fail to capture the feeling of one's Central Nervous System having lost the ability to regulate how we experience the world, its capacity to make our existence feel more-or-less comfortable (Kosten & Baxter, 2019). As a result, such metrics and comparisons consistently mischaracterize and underestimate withdrawal's capacity for producing dysphoria and pain (Fixsen (2016); Fixsen and Ridge (2017); Kopelson (2020)). Yes, withdrawal includes nausea and vomiting; sweating; gooseflesh; and the need to constantly 'kick' out your legs, but the real horror is feeling as though you cannot bear simply *being* for another second, every second. This 'feeling' is the result of complex biological, pharmacological, psychological, and social forces that are very hard to convey and resist quantification (Fixsen & Ridge, 2017; Kopelson, 2020). As one former benzodiazepine patient described "[Withdrawal was] hell and torture for every hour of every day for three years. I became so desperately ill that I find it very difficult to described what happened.... I could hardly walk; I couldn't have a shower because I couldn't stand for long enough. I could not tolerate sound or light. My entire body was affected from the top of my head to the tip of my toes. All these sensations were intolerable. I just wanted to die." (Brocklehurst, 2017).

The importance of listening to stigmatized patients

Recognizing the importance of experiential knowledge is particularly important when such knowledge concerns marginalized and/or stigmatized populations such as PWUD (Harris, 2020). Research has demonstrated how the uneven power dynamic between doctors and patients is even more so among PWUDs. This can negatively affect patients' willingness to attend treatment as well as their likelihood of being honest with medical providers (Ahern et al., 2007; Meyerson et al., 2021; Nwosu & Cox, 2000; Worthington & Myers, 2003).

Moreover, qualitative and ethnographic research has clearly demonstrated that people with unique experiences also have a uniquely important position from which to address them (Harris, 2020; Jamal & Hollinshead, 2001; Rhodes et al., 2012; Toolis & Hammack, 2015; Villenas, 1996; Wilson et al., 2016). Critical Race Studies; Gender Studies; Queer Studies; and Post-Colonial Studies; as well as research on stigmatized populations such as people seen as disabled, people who do sex work, and PWUD have all used 1st-person accounts to challenge dominant, often oppressive narratives and power structures in ways that would not have been possible using other methods (Charon, 2008; Chilisa & Ntseane, 2010; Lester & Nusbaum, 2018; Torre, 2009). Thus, in the same way that a white male should avoid presuming to understand the affective experience of racial and/or gendered violence, regardless of whether or not he holds a degree in Race or Gender Studies, doctors should exercise a similar caution when dealing with the issues that affect PWUD.

The frustration of marginalized groups with "experts" monopoly on knowledge production can be observed in the growing use of alternative, patient-generated sources of knowledge to address medical issues (Fixsen & Ridge, 2017). For example, online spaces like Benzobuddies.com and Erowid.com – forums where people with direct experience can post and respond to questions as well as share information on their own experiences with medications/drugs – often serve as DIY sources of healthcare information for PWUD (Groot & Van Os, 2020; Benzobuddies.org, 2020; Erowid.org, 2020; Fixsen & Ridge, 2017). I read them voraciously throughout my experience and while the quality of postings varies, I found the advice to be consistently cogent and useful. Many of the regular posters are well-read and familiar with the scientific literature (a small number are also involved with substance use research and/or treatment), but the real value of such forums comes from the wealth of expertise generated by lived experience.

Although such forums can also function as alternative sources of information for physicians, they are usually either discounted and/or ignored by the medical community. A quick scroll through the posts on BenzoBuddies.com reveals dozens of postings from individuals who see medical professionals as poorly informed and less competent than those with direct experience (Benzobuddies.com, 2020). Among the most common complaints is that doctors routinely underestimate the presence, and severity of withdrawal.

Importantly, I am not suggesting that patients who use substances are always correct in their assessments or that their claims should always overrule those of physicians. Similarly, I am not claiming that PWUD never lie, or seek to mislead their doctors. Indeed, because drug use is both criminalized and seen as a marker of “addiction”, lying is a virtual necessity for many people who use drugs (Frank, 2020; Harris & Rhodes, 2013). Rather, I argue that even within that context, doctors should place greater credence on the claims of those with lived experience. For example, Shared Decision Making (SDM) models, where clinicians and patients share the best available evidence and approach decisions collaboratively have demonstrated an ability to empower patients and improve their experiences with medical providers (Elwyn et al., 2012; Makoul & Clayman, 2006). Similarly, harm reduction approaches to treatment, which also place a greater focus on patient-centered care, should be utilized to much greater degree in medical settings, and particularly when working with PWUD.

Conclusions

This issue has particularly serious implications in light of current events. Due to the high levels of stress that many are experiencing because of COVID-19 and/or related political and racial stressors, doctors in the U.S. have been prescribing benzodiazepines and other dependence-producing drugs at rapidly increasing rates (Agrawal, 2020; Chiappini et al., 2020; Express Scripts, 2020). Since many are seeking them out as a specific response to current events, it is likely that they will not have extensive (or any) experience with their proper use and discontinuation practices. Thus, they will be less likely to recognize withdrawal symptoms for what they are and even less able to argue effectively against any claims made their doctors.

For those in substance use treatment programs such as methadone maintenance treatment, like myself, the situation can be even more fraught. Arguing against a treatment provider, where the power differential between doctor and patient is even more one-sided, could potentially put one's treatment in jeopardy (Caplehorn, Irwig, Saunders, & Chir, 1996; Frank, 2019; Strike, Millson, Hopkins, & Smith, 2013).

As a researcher with lived experience, I try to mobilize the cultural capital I have through my status as an academic to counter-act and deconstruct peoples' perceptions of PWUD. Thus, I have always been open about my status as someone with a foot in both worlds. Sometimes, as in this case, it works and I am able to affect the outcome in a positive way. Yet, just as often, the reverse is true and knowledge of my drug use or participation in MMT overwhelms my status as a scholar and expertise in substance use issues, and I am dismissed for that reason.

It is also important to point out that my doctor is not a bad treatment provider. In fact, he is a compassionate and competent physician, and compared to most methadone providers, approaches treatment from a common-sense, harm reduction perspective. Moreover, not only did he acquiesce fairly quickly, but has also used the experience as an opportunity to better understand the management of his patients' benzodiazepine use, something that many physicians would not have done. Yet, like all treatment providers, he is also part of a system that conceptualizes the claims and narratives of patients who use drugs through a particular lens that is not always conducive to positive healthcare outcomes.

As such, this is a systemic issue and a true solution will only occur once medical institutions re-assess their views on drugs and the people who use them. However, in the short-term, doctors could avoid a

number of problems by simply listening to and believing their patients more often. Additionally, doctors who deal routinely with PWUD should have access to a number of active (or at least former) substance users whom they can call upon for advice. The substance use forums discussed above should also be consulted regularly by any physicians who prescribe dependence-producing drugs. This, in addition to greater focus on alternative treatment models, like SDM, would go a long way towards improving medical outcomes for marginalized populations as well as helping to foster a relationship of trust and respect where better diagnosis and treatment plans can be made.

However, if this situation is not re-assessed and improved, large numbers of people currently prescribed benzodiazepines as a response to Covid-19 may find themselves in a similar position to the one I faced, only without the resources I had available to rectify it. Based on my own lived experience, it is not difficult to imagine large numbers of people leaping from their fire escapes.

Funding

This work was supported by the NIH/NIDA funded T32 training grant 5T32DA007233-35.

Declarations of Interest

The authors report no conflicts of interest. The author alone is responsible for the content and writing of the paper.

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