Potential Value of the Insights and Lived Experiences of Addiction Researchers With Addiction

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People in remission from substance use disorders (SUDs) have a history of using their own experience (also referred to as ''experiential knowledge'' or ''expertise'') to support those in or seeking SUD remission. In recent years, people with this experiential knowledge are being incorporated into research protocols to better guide research questions and inform the real-world uptake of SUD treatments and recovery supports. In these research contexts, however, those with research expertise and addiction rarely speak freely about these overlapping perspectives. The aim of this commentary is to increase awareness regarding the existence of this group (addiction researchers with addiction) and to explore the possibility that their expertise may help advance addiction science while helping to reduce stigma.

Key Words: addiction research, lived experience, stigma

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Personal histories can shape career interests and trajectories, including the decision to embark on a career in addiction research. An addiction researcher with a past addiction possesses an interesting, though complicated, combination of experiential and scientific expertise. If harmonized, these sources of expertise pose two possibilities; first, access to insights and understandings that are unavailable to addiction researchers without similar experiences; second, opportunities to reduce stigma and, ultimately, bring greater awareness to the human-ness and heterogeneity of addiction. The aim of this commentary is to open a conversation about addiction researchers who have histories of substance-use disorders (SUDs, a term we will use interchangeably with ''addictions''), and to explore what ways these researchers may utilize their experiences to help advance the biomedical research fields.

MORE OPEN DISCLOSURE OF LIVED EXPERIENCE MAY HELP GROUND (AND ADVANCE) THE SCIENCE OF ADDICTION

Epistemological and validity perils of using experiential knowledge notwithstanding,[1–2] phenomenological access to memories and states that characterize the continuum of drug use, drug addiction, and remission/recovery have not received enough open acknowledgment. However, greater efforts to incorporate lived experience are beginning to take place in studies and institutions focused on addiction. When the National Institutes of Health launched its Helping to End Addiction Long-Term initiative to address the opioid crisis, it sought a variety of stakeholders including patient advocates and people with addiction histories.[3] In the realm of clinical practice, people with addiction histories are frequently employed in peer-support roles, as bridges between acute and longer-term care, and as recovery facilitators.[4] The typical arrangement in all these contexts, however, is for nonprofessionals with ''experiential knowledge'' (eg, ''peer supporters,'' ''people with lived experience,'' ''consumers'') to be distinguished from those with scientific training and expertise. Is there a place for trained addiction scientists with ''experiential knowledge'' of their own? The answer, we believe, is a qualified yes.

Some of the ''yes'' is simply *de facto*: addiction researchers with addiction *already exist* in numbers that are probably not trivial, and their personal experience presumably informs their scientific thinking, albeit quietly.[5] Instances cited ''on the record'' are rare. One indirect example appears in a commentary by one of us, citing a personal account from a formerly opioid-addicted scientific colleague whose experiences helped refute an assertion that drug-seeking in humans is always goal-directed.[6] In addition to puncturing such overapplications of one-size-fits-all theories about addiction,

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scientists with addiction histories may also help improve working definitions for thorny concepts and constructs, such as ''compulsion'' and ''craving.''

For example, researchers with histories of addiction may have keen insight into the face-validity of animal models of addiction; this may include ideas for improving models by better incorporating immediate vs. delayed drug choices, ranked preferences and intentions, or motivating factors behind, the progression from use to addiction. The importance of context, and conflicted choice, is increasingly recognized among bench scientists who model addiction in laboratory animals,[7] but the recognition might have arrived sooner if their colleagues or trainees with addiction histories had felt more able, at the outset, to speak freely. Researchers with addiction could, for example, provide insight into the complex choice landscape involving tradeoffs between drug and nondrug reinforcers.

Another example is the disconnection between lived experience and most *human* research. Resolution of addiction symptoms is most often attributed to clinical intervention, though remission of addiction in humans is not at all the exclusive province of clinicians.[8] For example, decisions to reduce or discontinue use can sometimes happen spontaneously without clinical intervention[9]—spontaneous behavior changes might be better understood through the lens of people who have experienced them, and better operationalized to testable hypotheses from those who *also* possess research expertise.

Those of us who have conducted human research have noticed that beliefs about addiction are incorporated into every aspect of it—the framing of questions, the screening criteria for studies, the experimental manipulations used in human laboratory sessions, and the outcome measures used in clinical trials or assessment studies. Most of those beliefs are based on data and are defensible, but often they do not allow for the degree of heterogeneity that we know, from experience, is characteristic of addiction. More problematically, when research findings are interpreted, this heterogeneity is often just forgotten (eg, theories that fail in scope to represent the many experiences of addiction[6]).

We, as people with addiction histories or with experience mentoring trainees with addiction histories, contend that there can be an intersection of empirical research, theory, and philosophy where researchers with lived addiction experiences may help fashion a more comprehensive understanding of what it means to ''be addicted'' and to contribute to unreconciled conversations, like whether addiction is a disorder of choice, a chronic, incurable brain disease, or a bit of both.[10–12]

To be clear, this is not a call for abandonment of objectivity, rigor, and systematic study, nor a call to base our science on introspection and feelings. Beliefs are not facts and researchers with lived experience of addiction are likely influenced by personal biases just as much as researchers without direct lived experience of addiction. If these points are unrecognized, we risk doing harm by condoning an unchecked multitude of testimonially based claims (such that everyone can impressionistically decide what treatment is effective for them, be it horses or homeopathy).

So, when we posit that the lived experiences of addiction are a type of valuable insight that can be used to study addiction in ways that outside observation cannot, we believe such information must be judiciously considered as part of a broad epistemological inquiry. Lived experience may not be sufficient grounds for a theory, but it may be grounds for questioning theories that fail to encompass the heterogeneity of addiction.

THE LIVED EXPERIENCE OF DISCLOSING LIVED EXPERIENCE: STIGMA IS A PITFALL FOR DISCLOSERS, BUT ULTIMATELY A REASON TO DISCLOSE

It is increasingly evident, too, that there is much to be learned from people who belong to marginalized populations who have not yet been given a voice within major systems and institutions. A research environment that recognizes the value of insights from researchers with lived addiction experiences may not only produce more useful results, but also challenge stereotypes about formerly addicted people. Further, if one major aim of addiction research is to improve the lives of those with addiction, a concerted effort to support the training and career development of people with addiction histories is a direct way of doing so.[i]

But the process will not be easy. The historical moralization of addiction has contributed to longstanding public misconceptions that addicted people are wholly culpable for their SUDs. These misconceptions can inform public support for punitive measures in lieu of scientifically-informed interventions, contribute to inequitable institutional hiring and training policies, and influence how people with addiction histories view themselves professionally, including fostering doubts about perceived worth or capacity to make important scientific contributions. In other words, real and anticipated stress related to this particular devalued minority status. This can be extended to doubts about one's place within the greater community of addiction researchers. We can personally attest to the fact that SUD stigma can persist years after remission/recovery have begun and that opportunities and expectations are not always equally apportioned to those with known addiction.

Even *among* those with a past addiction, there will be unequal apportionment of the costs of disclosure. Disclosure may be especially difficult for trainees and early-career investigators who are minoritized or marginalized in other ways, or who belong to historically oppressed populations. As long as there is stigma attached to having a past addiction, most researchers with lived addiction experiences—even those who do not have to contend with the social and structural barriers that affect other minoritized groups—will have reasons to remain silent. Yet we also have the capacity to contribute meaningfully and uniquely to bench-to-bedside research, philosophical and policy conversations, and the ethical oversight of human research. With this commentary, we want to open the

[i]Most of the authors (S.W.S, K.E.S, D.P.E, N.V) have a history of having experienced various SUDs and each currently lives with different remission-recovery experiences. This underscores not only the heterogeneity of addiction, but also the heterogeneity of life following addiction (eg, some prefer the term ''recovery'' whereas others prefer the term ''remission''). D.H.E. has a history of lived experience with major depression (which he discloses to colleagues and trainees when it is pertinent to scientific discussions, as it often is); not coincidentally, he also has a belief that behavioural research should be informed phenomenologically as well as biomedically. He has also mentored trainees with addiction histories.

door slightly wider so that insights like ours can be brought to bear on the scientific process. Like any other type of information, such insights, however hard-won they are from our perspective, would need to be critically examined: good science should subject every idea to skepticism, critique, and dialogue. But skepticism, critique, and dialogue are different from outright dismissal, ridicule, or reprisal.

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