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Lived experience and the work we do

Christopher G Davey

As clinicians and researchers, our focus is on the lived experience of people with mental illness. Our guiding mission is to alleviate their suffering and to promote their recoveries, and we offer treatments and do our research with these aims in mind. This one-way relationship between clinicians and researchers on the one side, and people with lived experience on the other, is changing. The direction of influence is now flowing both ways, and the composition of each side becoming more fluid.

What is lived experience? In the mental health sphere, it is the knowledge of mental ill-health and recovery gained from direct, first-hand experience of it. It refers to 'mental health challenges that have caused life as we knew it to change so significantly we have to reimagine and redefine ourselves, our place in the world and our future plans' (Byrne and Wykes, 2020). Lived experience encompasses consumers and carers: those who have experienced mental ill-health first-hand and the family and friends who support them. If the phrase 'lived experience' sounds oxymoronic – can we have experiences that are not lived? – its intent is to draw attention to the fact that many people working in the mental health space have experience of mental illness by virtue of the work they do – as clinicians and researchers – and not through direct experience of mental illness itself.

Lived experience in clinical and research practice

The contribution that lived experience is making to the work we do is growing rapidly, and in mental health more than in other areas of medicine, which are following our lead. Mental health services employ people with lived experience as peer workers, drawing on their unique experiences of mental ill-health and recovery to help guide people who are currently unwell towards their own recoveries. People with lived experience play key roles in the co-design of contemporary mental health programs, ensuring that their perspectives are brought to bear in the way programs are delivered.

In research too, co-design is emerging as an important component of research practice. In the past, we have developed our ideas, obtained funding for them, and then implemented them without any input from people who have had experiences like those who will participate in our studies. This is no longer good enough, and although lived experience co-design is not yet mandated by bodies such as Australia's National Health and Medical Research Council, there is a good argument it should be. We should involve lived experience experts from the beginning – from the very conception of our studies – where they can provide genuine contributions to how they are designed.

Two sides less divided

We often talk about people with lived experience as if they exist in a separate domain from clinicians and researchers, with the very concept of co-design assuming that separate parties come together to engage in the process. But given the ubiquity of mental ill-health, there are many clinicians and researchers who have their own lived experiences. When we sit at a table with 10 colleagues, we might assume that 4 or 5 of us will have had our own experiences of mental illness, and another few will be key supports for people with mental illness. It is said that such first-hand experience doesn't of itself give a person the imprimatur to represent lived experience (Byrne and Wykes, 2020). Lived experience is its own domain, with a history and practice that provides representatives with a professional identity that is distinct from other mental health domains. The clinician or researcher at the table with their own history of mental illness will in many cases not share that professional history. This is not to say that such dual identities are not possible: many who have first identified as being part of the lived experience community have gone on to develop skills as clinicians and researchers.

The voices of those of us with lived experience of mental illness who have primary identities as clinicians and researchers are, however, less prominent. In part, this is due to the enduring stigma that adheres to mental illness. It requires that we make ourselves vulnerable to our colleagues, revealing something important about our private lives that we fear will make us appear less robust and capable. But the stigma that adheres to mental illness is slowly waning, and

Department of Psychiatry, The University of Melbourne, Carlton, VIC, Australia

Corresponding author:
Christopher G Davey, Department of Psychiatry, The University of Melbourne, Level 3, Alan Gilbert Building, 161 Barry Street, Carlton, VIC 3053, Australia.
Email: c.davey@unimelb.edu.au

prominent politicians, sportspeople, and media personalities have shown more comfort talking about their mental health experiences. In this atmosphere of acceptance and understanding, our mental health colleagues too are more willing to discuss their experiences. They bring with them rich perspectives informed by their clinical and research expertise.

Lived experience perspectives

ANZJP is keen to represent the lived experiences of clinicians and researchers working in the mental health space. In this issue, and in what I hope will be an occasional series, we present two articles. Paul Badcock is a lecturer and researcher in youth mental health who has written influential theoretical articles about depression, and he discusses here his experiences of mania as a young man (Badcock, 2023). It is a compelling account of manic psychosis, of which we have so few first-hand accounts. He describes his emergence from a deep depression, relieved and enlivened by a newfound verve and sociability. But his initially lucid state transitions into one where he loses his ability for reflection and insight as his energy becomes more fevered, until he encounters a mental health system that responds with an abrupt containment. His description of his mental state is raw and unsentimental, and it teaches us much about the extraordinary power of mania.

Israel Berger is a trainee psychiatrist who has written previously about his experience of depression (2022). He wanted to explore whether repetitive transcranial magnetic stimulation (rTMS) might be a useful treatment for his depression and was keen to learn what experiencing it might be like. Unable to find any first-hand descriptions of it in the academic literature, he sought to write about his own experiences of rTMS after he had completed a course of it (Berger, 2023). He found that rTMS helped his mood, but it wasn't an easy treatment to tolerate. It was uncomfortable, causing mild pain, odd visual experiences, and jaw clenching. But in his estimation, this discomfort was outweighed by the benefits he obtained, and his description of his experience of rTMS provides a valuable perspective for all of us.

In the spirit of openness exemplified by Badcock and Berger, I can say I have not yet sought mental health care for myself. But I do have experience of it as a carer of a child with complex developmental needs, including a diagnosis of autism, and know something of what it means to interact with the mental health system from the other side. This carer experience has opened up for me a new perspective on mental health care: seeing sometimes the strengths of our treatments and our mental health system, but perhaps more strikingly, seeing their limits. And it has deepened my empathy for what so many in the community endure.

Our capacity for empathy is part of what we seek to develop from those who share their lived experiences. But more than this, it is how we use those perspectives to reform and reshape mental health care. Too often our perspectives are viewed as operating in opposition, in part a consequence of the trauma experienced by people with mental illness who have been poorly cared for in underfunded mental health services, which has engendered an understandable anger – towards psychiatry especially. We have to respect that our perspectives are in many ways different, and find in those differences a more nuanced understanding of mental illness and mental health care. But our perspective can also overlap, and the shared experiences of those who understand clinical and research practice, on the one hand, and mental ill-health through direct first-hand experience, on the other, are especially valuable.

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ORCID iD

Christopher G Davey https://orcid.org/0000-0003-1431-3852

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