Rethinking the concept of insight

The psychiatric concept of insight involves recognition that one has a mental illness, that unusual mental events are pathological, and that treatment is needed. This concept has informed both research and clinical practice in several respects[1]. However, recent alternative perspectives on insight are emerging. These perspectives are rooted in the knowledge of people experiencing madness and extreme distress, referred to here as survivors.

Survivors have a long history of formally and informally coming together to share experiential knowledge. This includes through friendships, often formed in shared psychiatric spaces and more recently online social media spaces, inpatient and community-based service user groups, and global consumer movements. The Survivors History Group (studymore.org.uk/MPU.HTM) describes some of these initiatives. At the end of the 20th century, this sharing of experiential knowledge began to be formalized through survivor research.

Survivor research can be understood as the methodical and disciplined exploration of phenomena important to survivors, based on shared experiences and perspectives, leading to new collective and transferable knowledge. Survivor researchers are located inside and outside of academia, including in grassroots organizations, and in countries across the globe.

The overlapping field of Mad Studies has emerged in the last decade. Mad Studies is a fluid discipline that can broadly be understood as psychiatric survivors and their allies, such as critical practitioners, activists and academics, exploring and generating knowledge that is critical of current psychiatric practice and systems[2].

The emergence of survivor research and Mad Studies is creating new opportunities for survivors and others to explore experiential knowledge of madness, distress and extreme and unusual experiences.

Consistent with standpoint epistemology, both survivor research and Mad Studies entail privileging direct personal experience of phenomena, exploring the intersections and departures at broader levels, developing collective empirical and theoretical knowledge and, potentially, generating new understandings of concepts like insight.

In a recent Mad Studies publication, B. Filson described the consequences for personal meaning-making of being deemed to lack insight[3]: “I knew that what I was experiencing made sense, given what had taken place in my life. Even then I understood my reactions as sane responses to an insane world. I was told ‘Whatever else might be going on with you is not relevant – it’s your mental illness that matters’. This drove me into a frenzy, for now help was just another perpetrator saying ‘You liked it, you know you did; that wasn’t so bad; it’s for your own good’. I was diagnosed and described as ‘lacking insight’ – ensuring that I would never be able to legitimately represent myself or my own experiences.”

As Filson describes, being labelled as lacking insight can prevent credible self-representation and frustrate people’s exploration and understanding of their own stories. Whatever a practitioner’s motivations, and whatever the external unintelligibility of a person’s experiences, claims to epistemic authority silence those who have “stories to tell”[3].

This makes the concept of insight a core site of epistemic struggle. Epistemic injustice – discrimination against and exclusion of particular forms of knowers and knowledge – is widespread in mental health, in part because of the notion that psychiatric illness is defined by lacking insight. However, when experiential knowledge is privileged rather than disqualified, alternative and legitimate ways of conceptualizing insight emerge.

These alternatives begin with people as the owners of their own narratives, with the right to construct personal meaning and explanatory frameworks, alone and collectively. The Hearing Voices Movement, for instance, understands voice hearers as having ownership of their voices and their interpretation, with support given to explore personal meaning-making through spiritual, cultural, trauma or other broad frameworks[4].

From this perspective, insight is not an absence/presence or even a continuum, but an evolving and ongoing process of meaning-making, which may shift over time. This meaning-making process is culturally bound, in the same way that the clinical conceptualization of insight is culturally embedded[5].

When narrative insight – defined as developing a meaningful and useful narrative about one’s experiences within cultural contexts[6] – conflicts with the clinical construct of insight, institutional processes relating to the power to define experience become activated. Authoritative claims that others lack insight then become used to justify coercion and compulsion, in contravention of the human right to self-determination and narrative ownership.

One implication of this critique is that clinical practice frameworks are needed that support personal meaning-making: “The behaviours and thoughts that experts in some cultures label psychotic or schizophrenic are usually understandable reactions to our life events and circumstances. So rather than ask ‘What is wrong with you?’ and ‘What shall we call it?’, it is more sensible, and useful, to ask ‘What happened to you?’ and ‘What do you need?’”[7].

This indicates the need for trauma-informed approaches to be widely used in mental health systems. These approaches are based on the potential for trauma to be causal in a person’s current experiences, and consequently emphasize the need to create safety and to prevent harm and re-traumatization arising from service responses to distress.

One way of achieving this is to respond to people’s extreme experiences – which are often terrifying and debilitating – through listening and exploring, rather than denying their basis in reality. Having the support to situate unusual and frightening beliefs and experiences in one’s personal narrative is a foundation for post-traumatic growth and recovery[4]. This does not involve abandoning clinical expertise, but rather requires a balanced respect for practice wisdom[8] and for experiential knowledge.

A second implication is that clinical explanatory frameworks are not universal. Alternative explanatory frameworks exist, and it is simply not possible to know whether it is ultimately more beneficial to a person to frame his/her experience as, for example, a spiritual crisis, a trauma-related response, or an illness relapse. This is challenging, since some people experiencing mental health-related crisis actively want "psychiatric rescue", i.e. an authoritative institutionalized response which temporarily takes decisions on behalf of the person in order to restore stability.

However, the phenomenon of revolving door and the challenges of improving long-term outcomes in psychosis indicate the limits of any single explanatory framework. Therefore, any clinical explanation for experiences should be offered with tentativeness rather than authority, and clinicians might usefully sign-post service users towards alternative perspectives, such as Alternatives To Suicide, Hearing Voices Network, Mad Pride, positive psychotherapy for psychosis, post-traumatic growth, spiritual emergence, and trauma-informed approaches.

More challengingly, a focus on the experience of social exclusion may generate momentum away from individual-level explanations of experience and towards activities to generate collective action to improve mental health and social care system compliance with human rights legislation[9]. Modesty in clinical knowledge claims is empirically justified.

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An update on Individual Placement and Support

Disability experts and public officials in countries around the world now acknowledge that people with chronic health conditions and disabilities, including serious mental illnesses, have a right to participate fully in community life, including regular employment. Employment is not only a determinant of health and well-being, including mental health[1], but also an antidote to social exclusion[2].

Individual Placement and Support (IPS) has become the standard of supported employment for people with serious mental illness, such as schizophrenia and bipolar disorder. It incorporates eight core principles that have been well researched with a validated fidelity scale used worldwide for quality improvement purposes[3].

These principles are: a) focus on the goal of competitive employment (agencies providing IPS are committed to regular jobs in the community as an attainable goal for clients seeking employment); b) zero exclusion (every client who wants to work is eligible for services regardless of "readiness", work experience, symptoms, or any other issue); c) attention to clients' preferences (services align with clients' choices, rather than practitioners' expertise or judgments; IPS specialists help clients find jobs that fit their preferences and skills); d) rapid job search (IPS programs help a client look for jobs soon after he/she expresses interest in working, rather than providing lengthy pre-employment assessment, training and counseling); e) targeted job development (based on clients' interests, IPS specialists build relationships with employers through repeated contact, learning about the business needs of employers, and introducing employers to qualified job seekers); f) integration of employment services with mental health treatment (IPS programs closely integrate with mental health treatment teams); g) personalized benefits counseling (IPS specialists help clients obtain personalized, understandable and accurate information about how working may impact their disability insurance and other government entitlements); h) individualized long-term support (follow-along supports, tailored for the individual, continue for as long as the client wants and needs them to keep a job or advance career opportunities).

Evidence for the effectiveness of IPS continues to grow, starting with early studies in the US in the 1990s and 2000s and extending to replication studies throughout Europe, Canada, Australia, Hong Kong and Japan. IPS is the most extensively and rigorously researched of all employment models and the only evidence-based employment model for people with serious mental illness.

In 28 randomized controlled trials assessing the effectiveness of IPS for people with serious mental illness, all but one in mainland China found competitive employment outcomes significantly favoring IPS. Across the 28 studies (N=6,468), 55% of IPS participants achieved competitive employment, compared to 25% of control participants receiving other vocational services (https://ipsworks.org/index.php/evidence-for-ips/).

Over the last decade, a number of systematic reviews and meta-analyses have confirmed this basic finding[4,5]. One meta-analysis reported moderate to large effects favoring IPS for a range of other employment outcomes[5]. Another meta-analysis found that, compared to control participants, IPS participants gained employment faster, maintained employment four times longer during follow-up, earned three times the amount from employment, and were three times as likely to work 20 hours or more per week (https://ipsworks.org/index.php/evidence-for-ips/).

Long-term studies show that half of all clients enrolled in IPS become steady workers, maintaining employment for 10 years or