





GUEST EDITORIAL

Ethics and stigma in psychiatric research

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Advancement in almost any field, including psychiatry, is underpinned by research. It brings benefits in terms of improved care, through better treatments, medications, and service delivery. Research forms the basis of evidence-based healthcare. In the realm of psychiatric research, the intertwined issues of ethics and stigma present formidable challenges (1). This requires us to navigate complex ethical landscapes and confront pervasive societal stigmas (2–4).

The burden of mental illness is immense, impacting patients, their families, communities, and the economy. Unfortunately, stigma and discrimination, age-old burdens impacting those living and dealing with mental illness, have led to disproportionately negative funding biases for psychiatry compared to other areas of medicine. Stigmatizing attitudes have infiltrated the realm of psychiatric research, impacting patient recruitment, funding priorities, and public perceptions. Thus, stigma can skew funding for services and research, adversely affecting service delivery (5, 6).

Research involving human participants is a privilege grounded in trust. For many years, there has been increasing awareness of the ethical principles surrounding research, especially research involving human participants with mental illness. Various organizations have considered these issues and provided guidelines and best practices. Fundamental to these are four principles: respect for persons, autonomy of persons, beneficence, and justice (7).

Individuals with mental illness need to have a voice, in that they should be represented in study samples and on committees reviewing research applications. Including individuals with mental illness

in research populations also means they should not be actively excluded from study populations by virtue of their illness. Investigators should not only be well-schooled in research methodology but should also be well-schooled in the ethical principles of conducting research with people with mental illness, especially when unwarranted assumptions and generalizations can impact the understanding of the vulnerabilities and, conversely, the strengths of the patients they study (psychiatric services). There can sometimes be dual challenges for researchers, as external stigma needs to be combated while mitigating internal biases. Perceived preconceptions or notions, and stereotypes about mental illness can influence study design, data interpretation, and researcher-participant interactions. These biases can not only compromise the validity and generalizability of research findings but can also perpetuate harmful narratives that reinforce stigma. Pressure to recruit may lead to the temptation to gloss over or ignore the importance of fully informed consent for research. Financial and career benefits can create a conflict of interest, increasing participants in study recruitment.

Ethical research requires a commitment to equity and justice, especially in the recruitment and representation of populations that have been historically marginalized. Vulnerable groups such as racial minorities, LGBTQ+ individuals, and those with associated economic disadvantages have all been disproportionately negatively affected by mental health stigma and discrimination. It is contingent upon those of us doing research to redress these disparities and ensure that their voices are amplified, especially those who have been silenced by stigma.

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Informed consent and decisional capacity are key areas that require safeguards. As decisional capacity may vary over time, ongoing monitoring during the study is necessary, especially for longer studies. Key areas of concern are when placebos are used or when treatment as usual may be compromised. Risks need to be clearly outlined, and if an investigational treatment proves effective, funding for ongoing post-study treatment needs to be in place. All communications to patients need to be in plain language and free from jargon (8, 9).

Psychiatrists need to advocate for their patients when their voices are muted, whether through illness, stigma, or discrimination. They should not be excluded from research individually or collectively. Conversely, psychiatrists need to be able to speak up for their patients to ensure they are protected when decisional capacity may be impaired. Bias, implicit or explicit, needs to be considered, and all research involving people with mental illness should be governed by regularly updated guidelines or published best practices. The education of researchers, patients, and their families about the ethical principles underlying psychiatric research is essential, especially when research is conducted on people with mental illness. Awareness of stigma and discrimination will empower future researchers as they seek to improve outcomes for their patients, specifically those dealing with mental illness.

Underpinning all of this is a compassionate approach. This involves recognizing the inherent worth and humanity of all individuals with psychiatric conditions, transcending labels and stereotypes to cultivate a genuine understanding and empathy. Practically, this involves a collaborative partnership with diverse stakeholders, including individuals with lived experience, advocacy groups, and healthcare providers. It is important that researchers consider the principle of reflexivity, wherein they examine their own attitudes, assumptions, and privileges.

By cultivating self-awareness and humility, researchers can guard against the insidious influence of stigma and ensure their work is guided by principles of fairness, inclusivity, and social justice. As a call to action, researchers and psychiatrists in general should confront stigma at every turn, working towards a future where research is methodologically rigorous and ethically sound.

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