

Ethical issues arising in research with people with mental health conditions

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Case study

Ethical implications of using family key-informants to understand the transgenerational impact of severe mental illnesses in rural Ethiopia

Wubalem Fekadu¹ (presenter), Tom K.J. Craig², Abebaw Fekadu¹

¹ WHO Collaborating Centre for Mental Health Research and Capacity Building, Department of Psychiatry, College of Health Sciences, Addis Ababa University, Addis Ababa, Ethiopia

² Department of Health Services and Population Research, Institute of Psychiatry, King's College London, London, UK

Description of the research project

The aim of our mixed methods study was to explore lived experience of people with severe mental illness (SMI; psychotic disorder, bipolar disorder and major depression), their family members and community members and to compare the transgenerational impact of illness (multidimensional poverty, mortality, food insecurity and family satisfaction) between households of people with SMI and matched (sex, age (± 5 years)) control neighbors in rural Ethiopia.

We nested this study within an existing population-based cohort on SMI in two predominantly rural districts of Meskan and Mareko Southern Nations Nationalities and People's Region (SNNPR), Ethiopia. The population of the two districts is over 300,000. Healthcare is provided from one general hospital, 13 public health centers, and several private clinics. Mental health care is provided in the hospital psychiatric outpatient clinic staffed by psychiatric nurses. Participants (n=919; 358 with schizophrenia, 346 with bipolar disorder, and 215 with major depression) were recruited between 1998 and 2001. Extensive evidence has been generated from the cohort, including on premature mortality, the clinical course of schizophrenia, suicide, and suicide attempts among people with SMI, as well as nested trials.

We collected data from three sources for the qualitative study: people with SMI, their family members and community members. This helped us to understand the multiple perspectives on the situation. For the quantitative study, we used one adult key informant nominated by the household members, including the person with SMI, to collect the data. With the help of the participant, we drew up a detailed family tree and used this as a framework to acquire the necessary information (on economic status, living standard, food security, mortality, and education).

Ethical issues

People with SMI expressed disappointment when they were left out of the conversation either in the clinic or in the research context. We explored the perspectives of individuals with the illness, and they expressed that:

- 1) They can speak for themselves
- 2) Their family members may tell the researcher or clinician "my secret"
- 3) The interviewer may share their secrets

This concern is legitimate because the participants have the **right to know and decide for themselves (autonomy)**. Active engagement with people with SMI also has the potential to improve therapeutic alliance in the clinic and trusting relationships that produce credible data in research. The possible justification for not involving people with SMI is the concern that they may periodically experience symptoms that interfere with gaining reliable information, especially during the acute and relapse phases.

People with SMI and their family members reported deep-rooted stigma and discrimination in the public against them. Community members acknowledged the pervasiveness of stigma, but they did not think it was a priority. Community members reported that people with SMI and their family members were excluded from support systems, such as financial safety net programs, in addition to other forms of stigma and discrimination. The issue we faced in interviewing community members was **maintaining anonymity**. We interviewed the community members after interviewing people with SMI and their family members. We conducted the interviews one week apart and we did not notify the community members about our interview with people with SMI and their family members.

Conclusion and recommendations

Autonomy, privacy, human rights, and equality are the major ethical challenges in mental health research. The main lesson from our project was that allowing people with SMI to speak for themselves affirms agency and has the potential to encourage therapeutic alliances and research engagement. Despite heavy reliance on families for social and healthcare, it is important to ensure people with SMI have the right to be involved in research and mental health care. However, it is critical that researchers ensure anonymity when involving people with SMI and the community members in a similar research project.¹ Other initiatives from Ethiopia to equip and empower people with SMI for self-advocacy may facilitate involvement of people with lived experience of SMI in the planning and execution of research projects, as well as being the subjects of research. Research may also have potential to drive change within community's community advisory boards for projects are one way to increase wider awareness and engagement of the community in supporting people with SMI, and to facilitate community mobilization to address emerging issues.²

References

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2. Fekadu A, Hanlon C, Medhin G, Alem A, Selamu M, Giorgis TW, et al. Development of a scalable mental healthcare plan for a rural district in Ethiopia. *The British Journal of Psychiatry*. 2016;208(s56):s4-s12.

This case study was prepared for GFBR 2021, which took place virtually. Further details are available at www.gfbr.global.