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ADDIS ABABA UNIVERSITY

AMARI
African Mental Health
RESEARCH INITIATIVE

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

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Introduction

- **There may be particular ethical challenges working with people with severe mental illness**
  - In close-knit communities
  - Where stigma is high
  - Where families take a dominant role in decision-making

Aim of the project

- **To explore lived experience of people with severe mental illness, their family members and community members**
- **To investigate the transgenerational impact of illness**
  - Multidimensional poverty
  - Mortality
  - Food insecurity and family satisfaction
- **Compared households of people with SMI and matched controls in rural Ethiopia**

Project overview

- **The project was nested within an existing population-based cohort on SMI**
  - Established between 1998-2001
  - Two predominantly rural districts of Meskan and Mareko
  - Mental health care is provided in the hospital psychiatric nurse outpatient clinic

Project overview

- **We collected data from three sources for the qualitative study**
  - People with SMI, family members and community members
  - Multiple perspectives on the situation
- **For the quantitative study**
  - One adult key informant nominated by the household members
  - Family tree used as a framework

Ethical concerns Involvement and privacy

- People with SMI **expressed disappointment** when they were left out of the conversation
- Perspectives of individuals with the illness
  - **They can speak for themselves**
  - **Their family members may tell the researcher or clinician "my secret"**
  - **The interviewer may share their secrets**

Autonomy

- **Who decides who can talk about a person?**
  - Right to know and decide for themselves
  - Decide who else speaks about them
- **Active engagement with people with SMI**
  - Has the potential to improve therapeutic alliance in clinic
  - Trusting relationships that produce credible data in research
- **Possible justification for not involving**
  - Periodically relapsing symptoms that may interfere with capacity to consent and affect recall of past events

Discrimination and anonymity

- **People with SMI and their family members reported**
  - Deep-rooted stigma and discrimination in the public against them
- **Community members reported that**
  - People with SMI and their family members were excluded from support systems, such as financial safety net programs
- **Anonymity difficult in a close-knit community but essential to prevent social exclusion**

Conclusion and recommendations

- **Major ethical challenges in mental health research in our setting**
  - Autonomy
  - Privacy and maintaining anonymity
  - Human rights
  - Equity

Conclusion and recommendations

- **The main lesson from our project**
  - Allowing people with SMI to speak for themselves and decide who can speak about them
  - It is important to uphold the right of people with SMI to be involved in research
  - It is critical that researchers ensure anonymity when involving people with SMI and other community members in the same investigation

Other initiatives from Ethiopia

- Empowerment activities to support involvement of people with lived experience of SMI in the planning and execution of research projects, as well as being the subjects of research

Abayneh et al. (2020)

- Research can drive change within communities
  - E.g., Community advisory boards for projects can reduce stigma and expand access to mental health care

Fekadu et al. (2020)

Thank you

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