

Exploring the apparent absence of psychosis amongst the Borana pastoralist community of Southern Ethiopia. A mixed method follow-up study

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There are few reports of the prevalence of psychotic disorders among isolated population groups. Where present, variations in prevalence estimates raise questions about the validity of methods of case ascertainment in such settings. In a previous population-based survey of the Borana pastoralist community in Ethiopia using the Composite International Diagnostic Interview, no cases of schizophrenia were identified. In order to further explore this finding and investigate how serious mental disorder is conceptualized, we conducted focus group discussions with key members of the Borana pastoralist community. Subsequently, focus group participants were used as key informants to identify cases with possible psychotic disorder, based on their conceptualization. Cases identified by key informants were interviewed by a trained psychiatrist using the Schedules for Clinical Assessment in Neuropsychiatry (SCAN), to confirm presence of disorder. Focus group discussions were subjected to thematic analysis. The incongruity between local and psychiatric concepts lay mainly in the fact that key informants described characteristics of marata ("madness") in terms of overt behavioural symptoms. Following the focus group discussions, participants identified eight individuals with schizophrenia and 13 with a psychotic mood disorder, confirmed through SCAN interview. Studies of psychotic disorders in such communities are likely to benefit from combining structured interviews with the key informant method.

Key words: Psychotic disorders, Borana community, key informant method

(*World Psychiatry* 2010;9:98-102)

In recent years, a number of methodologically sound meta-analyses have challenged long-standing assumptions about the incidence, prevalence and outcome of schizophrenia in different cultural settings (1,2). In addition to environmental, psychosocial and biological factors, variations in reported incidence and prevalence could result from differences in the methodologies employed across studies, ranging from clinical case record surveys to community-based samples assessed with structured diagnostic interviews (3-5). Furthermore, current approaches to the classification of symptoms and syndromes have been criticized for being heavily biased towards European and North American cultural norms (6,7). These factors highlight the methodological challenges in generating directly comparable estimates of the prevalence and incidence of schizophrenia and other psychoses in non-Western settings.

The Composite International Diagnostic Interview (CIDI) is recommended as an instrument of choice in epidemiological research where the goal of the study is to draw comparisons about prevalence with other areas. It has been reported to be a reliable and valid instrument for both clinical and community based studies, appropriate for use in different settings and acceptable across cultures (8,9). However, because of the difficulty of diagnosing psychotic disorders using a structured interview in isolation, clinical re-interviews are encouraged in epidemiological studies (10-13).

In our previous study among the Borana semi-nomadic community in Ethiopia, using the CIDI, the lifetime prevalence of ICD-10 generated mental disorders was reported to be 21.6%, but no case of schizophrenia or other psychotic disorders was detected (14). On the face of it, these findings

support the idea that there are pockets of high and low prevalence of psychotic disorders (15), with the possibility of complete absence in some communities.

The current study was designed to re-examine this earlier finding. We conducted a two stage investigation: a) key informant interviews to explore local understandings of severe mental disorders, and b) ascertainment of cases of possible psychosis by the key informants, followed by clinical interview using the Schedules for Clinical Assessment in Neuropsychiatry (SCAN, 16). We hypothesized that the initial finding was a consequence of methodological bias, and that local beliefs, perceptions, and understandings of symptoms of psychosis were such as to produce negative responses to psychosis-related questions on the CIDI.

METHODS

The Borana pastoralist study area is a remote, rural region with poor infrastructure, and no mental health services. The Borana are among the few nomadic groups that still exist in the world today. They reside in all but two districts of the Borana zone, extending over a savannah grassland area of more than 400 km diameter in the southern part of Ethiopia, bordering Kenya. The Borana move around in search of grazing land and water for their cattle, especially during severe periodic drought seasons, which occur as frequently as every two to three years, and mostly live on milk and meat.

The study was conducted in the villages of Megado, Dida Yabello and Dida Hara, with combined populations of 10,598 aged over 18 years, where the earlier CIDI interviews were

conducted. It was a mixed-method study involving both qualitative methods (focus group discussions) and a structured diagnostic component using key informants for case finding.

In total, 56 key informants were invited to participate in the focus group discussions. Six groups of informants, each consisting of between 8 and 10 participants, were organized in each of the three study sites or villages. The inclusion criteria were: men and women of age 18 and above, resident in one of the villages for over two years, formal or informal community leaders or generally respected individuals with whom the researcher could communicate for information exchange. Visits to the study sites were made prior to the date of the focus group discussions to ensure that all the villages were represented in the groups.

Based on the inclusion criteria, two groups, one of men and one of women, were organized in each study site. The participants were informed about the study, and their willingness to participate was ascertained before the group discussion was started.

The focus groups were conducted by a moderator and a note-taker, both of them psychiatrists, who speak the local dialect. The group discussions were held in a local health care centre (2 groups) or community meeting area (4 groups). The discussions followed a topic guide using a series of open-ended questions regarding awareness, symptoms and causes of severe mental illnesses, and traditional ways of caring for severely mentally ill persons. They lasted between 45 and 80 minutes. In all groups, the facilitator encouraged participants to become actively involved in the discussion and ensured that each participant was given an equal chance to contribute. At the end of each group discussion, participants were asked to identify individuals living in their neighborhood who, from their perspective, met local criteria for madness or severe mental disorder.

All the proceedings were tape-recorded. A person who was fluent in the local dialect transcribed the discussions. The local transcripts were then translated into English by a psychiatrist and the accuracy of the translations was cross-checked by another psychiatrist, who has a good command of both languages and was brought up in the Borana area.

The analysis proceeded through a process of detailed reading, annotating and categorizing of transcripts to identify themes relating to the key areas of interest, i.e., terms and concepts, causes, treatments. Two psychiatrists independently coded each transcription manually. Any discrepancies were discussed and consensus on the appropriate coding reached. The interpretation of the data was discussed and agreed by the researchers before the write up.

All individuals who were identified by the key informants and who consented to be interviewed by the clinician were assessed in a health post facility or in their homes using the SCAN, the purpose being to explore the degree of congruence in case-definition between key informants and the psychiatrist. Clinical diagnoses were generated based on DSM-IV criteria. Sociodemographic correlates of SCAN-inter-viewed cases were analysed using SPSS 13.

Ethical clearance was obtained from the Ethiopian Science and Technology Agency (ESTA). All necessary information regarding the purpose of the study was given to the participants and, in cases where the subjects were acutely unwell, to their first-degree relatives. All participants gave informed consent. Any individuals requiring medication for mental disorder were treated on site, with referral for follow-up as indicated.

RESULTS

Fifty-six key informants were invited to the focus group discussions, of whom 49 (87.5%) participated. Twenty-six (46.4%) were female. The age of the participants ranged from 25 to 60 years (mean±SD 37.0±17.7 years). The majority of participants had never been to school, except for three who had received elementary level education.

Although a few participants reported that they had never heard about or known a person with severe mental illness, as the discussion progressed, all openly discussed their experiences of having known such individuals.

Participants gave a local name to the illness they described as constituting severe and disabling mental illness (*marata*, literal translation “madness”) which seemed to have broad conceptual equivalence to Western notions of psychosis. All participants accepted the term and there was no alternative terminology suggested for such illness. Participants differentiated *marata* from temporarily occurring culture-bound conditions such as *sarki*, that are considered to be more common.

This is called marata. It is different from sarki. A person could become marata for no apparent reason. Marata comes later in life, after the person has matured. When the person becomes marata, he behaves differently. No one knows what caused his madness for sure. He is marata... he runs around aimlessly, burns houses, beats people, and he snatches things from people.

One female participant described behavioural disturbance following alcohol use: “some people become mad only when they drink alcohol ... they become mad again whenever they drink some [more] alcohol”. Emotional disturbances were also reported to be associated with childbirth and adverse life events, such as the death of a loved one. Participants also differentiated recurrent or chronic mental illnesses from those caused by acute febrile conditions, which are common in the area.

One participant distinguished different courses of *marata* as follows: “For instance, one kind doesn't get better once [they develop] *marata*, hence they die *marata*, while the other kind gets better with treatment”. However, in general, nearly all participants agreed that once a person became mentally ill, he would not be cured. This assertion was supplemented by a common local proverb that says “*maaran hin*

magaallaa malee, hin fayuu ("Marata can get better but may never be cured"). Only a few participants gave examples of people who had just one episode of illness and recovered.

Observable behavioural symptoms were reported to be markers of *marata* by all participants. Besides physical violence and aggression, participants agreed that such behaviour could include disturbed feeding habits. For example: "He would eat non-edible things such as soap. He would eat everything, wild beasts, snakes...".

Aggressive and violent behaviour that is completely out of control, involvement in situations that could endanger self, others or animals, restlessness and being always on the move or roaming, disorderliness in the ways a person dresses, speaks and socializes with others, and unusual or abnormally quiet behaviour were all described and agreed by all participants to be markers of severe mental disturbance.

Some participants described behavioural disturbance as an easy way of detecting mental illness. An elder woman said: "It is easy to recognize a *marata* person. His behaviour would be changed. He would speak differently. A previously peaceful person would turn aggressive for no apparent reason". But others described aggression and behavioural disturbances to be periodic. One participant gave a description of behaviour in a person whom he knew well.

He sometimes looks healthy. He wouldn't attack people. He would walk quietly. There is another one who doesn't talk too much; he would say one thing and then he keeps quiet. There are times when he would become aggressive. The man I told you about earlier, the one who killed cattle, wouldn't talk to people. He would sit quietly. One morning, he started to chase the cattle and people. A mad person can't stay quiet for a long time. He will become ill one day.

Violations of social norms were also considered to be abnormal, whether occurring within the family or in other social settings.

She looks at people with one eye. She wouldn't talk to people. She wouldn't respond even if you called her name. People stand in line and take turns when collecting water from a spring. She wouldn't stand in line. She would come straight to the spring and take water without standing in line....

In addition to nonsocial behaviour, the person's speech was described by nearly all participants to be indicative of abnormalities.

The other symptom is shouting... He would shout and run... People would say the person has become mad when he shouts... When he starts to mix up things about Kenya and Ethiopia, Borana would say the person is taka marata... That means the person is developing madness.

Little emphasis was given to thought and perceptual disturbances in describing *marata*. Overall, behavioural changes seemed to dominate the symptom profile. Only one participant described feelings of fearfulness and paranoid thinking: *This man developed the illness just recently. At the beginning, he started to be fearful. He started complaining of being followed... He says people follow him and insult him, someone walks by his side and insults him*".

Some participants described loss of capacity to work, care for self and family, and gross deterioration in all spheres of functioning as being a consequence of *marata*.

He was a hard-working man: he would plough the farm and dig water wells. Now, he is out of his mind... He doesn't recognize anything. He would go out of his home and would come back naked, throwing his clothes away. He can't recognize his wife or children. Previously he was a normal person.

In all groups, participants openly discussed examples they knew of mentally ill persons who had either committed suicide in recent years or who had migrated to nearby towns.

There was an old lady who drank poison in this village. She was marata. She survived after drinking poison. But later on she died after hanging herself. This happened 4 or 5 years ago.

In all groups participants gave accounts of knowing someone with severe mental illness from their villages who had migrated to the towns around and also tried to give possible reasons.

Mad people like noise and they would run to town. They are better tolerated in town. People in towns give them food... maybe people who live in town are not afraid that these people would burn their houses. They wouldn't chase them away like we do ... that is why they run to town.

Sixty-five individuals were identified by the key informants. Out of 65 individuals approached, 48 (73.8%) adults, age range 18 to 80 years, were assessed. Two individuals were not willing to come for the interview, while the remaining 15 were not found at home after repeated visits. Of all the individuals interviewed by the psychiatrist, 36 (75.0%) had a DSM-IV axis I diagnosis. Eight (16.8%) had schizophrenia, 13 (27.1%) had a psychotic mood disorder, and 2 (4.2%) had brief psychotic disorder. Thirteen (27.1%) had a non-psychotic mental disorder (mood, anxiety or substance-related disorder or dementia).

DISCUSSION

Using a two-stage design, this study aimed to explore local concepts and understandings of severe mental illness in the



Borana pastoralist community in Ethiopia, and to further examine the previously reported absence of psychotic disorder in this setting (14). In our earlier population-based survey, the overall prevalence of psychiatric disorders, assessed using the CIDI, was 21.6%, with no case of schizophrenia. In this current study using Borana key informants, there was widespread awareness of severe mental illness, approximating Western conceptualizations of psychosis. Key informants identified twenty-three SCAN-confirmed cases of psychotic disorder, including eight cases of schizophrenia.

As with many other lay interviewer administered instruments, the major limitation with the CIDI is the poor validity in detecting psychotic symptoms (9,12,17). In the face of impaired cognition and judgment, psychotic patients may deny illness and respond negatively to such structured questionnaires, unless they are augmented by other methods. The validity of the CIDI in general population samples (17) and in non-literate non-Western populations (18) has also been questioned.

Key informants have been used in a few psychiatric studies for case detection both in high-income (19,20) and low-income countries (12,21). In an earlier study in Butajira, Ethiopia, CIDI and key informant methods were used for first stage screening of a large epidemiological study. The two methods were compared with regard to their case detection capacity and it was reported that the key informant method was significantly superior to CIDI, with greater sensitivity for identification of cases of schizophrenia (12).

The use of key informants for case detection in a similar previous study in Ethiopia reported that such informants are highly knowledgeable about mental health problems and the occurrence of cases in the neighbourhood (22).

In the current study, the majority of those identified by key informants as being *marata* ("mad") fulfilled criteria for a variety of axis I DSM-IV disorders, but not necessarily psychosis. The key informants were knowledgeable about symptoms of mental illness and held concepts which to some extent overlapped with those held by professionals. The incongruity between key informants-identified cases and the clinical assessments arose mainly because key informants tended to describe the characteristics of *marata* in terms of overt behavioural symptoms while underreporting symptoms related to thought disturbance. This contrasts with Western conceptualizations of psychosis, as reflected in the CIDI, which rest primarily on the presence of delusions and hallucinations.

In our opinion, the use of qualitative methods for attempting to understand local descriptions of severe mental illness appears to be superior to case-detection relying upon presentation of vignettes based on Western conceptualizations of disorder. Furthermore, attempts to explain the variation in prevalence of psychosis across cultural settings need to consider local conceptualizations of symptoms and disorder before concluding that true differences exist. In our study, although general concepts of severe mental disorder in the Borana pastoralist community reflected traditional beliefs,

especially with regard to the attribution of the illness and recommended interventions, there was significant overlap with the Western clinical models of psychosis in terms of speech and behavioural disturbances, as well as social and occupational dysfunction.

Symptoms of severe mental illness and, based on these symptoms, individuals with psychotic disorder were easily identified by key informants. One major difficulty in relying on local concepts of *marata* is that this concept seems to be broader and more all-encompassing than Western concepts of psychosis. As a consequence, some individuals with no mental disorder or who were suffering from non-psychotic conditions when assessed by clinical interview using SCAN were labeled as *marata*. In addition, the strong local belief that *marata* can only improve and never be cured could potentially lead to stigmatization of all emotionally disturbed individuals irrespective of the cause, diagnosis and course.

Cases of psychosis may have been missed in the original study for various other reasons. Some cases were missed in the sample selection. Re-examining the CIDI data from the previous study, we discovered that four of the cases with psychosis identified by the key informants had not been interviewed by CIDI. As noted by the key informants, persons with severe mental illness may become vagrants and migrate to cities, and are also at risk of premature mortality through suicide. Other cases were interviewed by CIDI but denied illness. In this category we have one case of chronic schizophrenia who denied any illness at all. Some further cases were interviewed but reported sub-threshold symptoms that did not fulfill the diagnostic criteria for schizophrenia: we found three cases in this category. Finally, methodological bias may have been involved, i.e., uneasiness, distrust and misunderstanding of the CIDI items due to difficulties comprehending the terminology.

The main limitation of this study is that the time period between the CIDI interview and the current key informant interview was over six years, making the comparison of the two methods difficult. Nonetheless, identification of psychotic disorders in this community provides evidence that psychosis occurs in this population group. Most of the cases identified had a long duration of illness and the symptoms had been present during the CIDI interview.

In conclusion, our data suggest that studies of psychotic disorders in isolated communities are likely to benefit from combining structured interviews with the key informant method.

Acknowledgement

This study was funded by the Stanley Medical Research Institute, USA. We would like to thank all individuals who participated in the study. Charlotte Hanlon is also acknowledged for editing an earlier manuscript.





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