Estimating Clinically Relevant Mental Disorders in a Rural and an Urban Setting in Postconflict Timor Leste

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Context: Epidemiologic studies undertaken in postconflict countries have focused primarily on trauma-related disorders. There is a need to include disabling psychotic disorders in order to plan clinical services in these settings.

Objectives: To estimate the prevalence of key clinical disorders in Timor Leste (East Timor), and to assess cultural factors that may influence help-seeking patterns.

Design, Setting, Participants: A 2-phase total population survey of 1544 adults in an urban and a rural area of Timor Leste. Phase 1 involved a household informant survey using indigenous terms to detect psychosis and a screen of all adults for posttraumatic stress disorder (PTSD) and symptoms of psychologic distress, including depression and anxiety. In phase 2, clinicians interviewed all those identified by household informants and half of those who screened positive in order to assign DSM-IV diagnoses. Disability, explanatory models, and perceived needs were also assessed.

Main Outcome Measures: Phase 1: Demographic characteristics; trauma events and PTSD (Harvard Trauma Questionnaire); psychologic distress (Kessler-10 scale).

Phase 2: Structured Clinical Interview for relevant DSM-IV diagnoses; the Global Assessment of Functioning Scale and the World Health Organization Disability Assessment Scales; and the modified Short Explanatory Model Interview.

Results: The household informant method in phase 1 detected mainly psychotic disorders, and the screen method detected PTSD and depression. Phase 2 yielded a DSM-IV point prevalence estimate of 5.1% (including psychosis, 1.35%; and PTSD, 1.47%). Psychotic disorders were most disabling, primarily attributed to supernatural causes and treated mainly by traditional healers. Those with depression and PTSD experienced substantial disability but had received little treatment. They attributed their mental problems to social and traumatic causes.

Conclusions: Our 2-phase method proved effective for identifying the range of disorders relevant to planning clinical services in postconflict developing countries. The unmet needs of the mentally ill in countries such as Timor Leste pose a major challenge to psychiatry.

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studies undertaken in low-income countries exposed to recent conflict.17

Identifying the prevalence of psychosis at the community level is especially challenging, however. There is a growing consensus that applying brief self-report screens to detect psychosis produces unacceptably high rates of false positives and false negatives.16,18-20 Accurate detection may be made more difficult in animistic cultures such as Timor Leste where it is normal to communicate with spirits and ancestors.

Researchers in developed countries have addressed the problem by devising specific low prevalence methods for detecting psychosis, identifying patients in settings of concentration, particularly in psychiatric clinics and support services for the mentally ill.21 These approaches are not feasible in countries such as Timor Leste, where there are virtually no mental health services. In traditional societies, most persons with psychosis are cared for by their families. We, therefore, based our case-finding approach on the reports of family informants.

An additional issue is that there may be little familiarity with Western terms for psychosis in countries such as Timor Leste. We, therefore, adopted an approach used in other transcultural settings,22-24 namely, to present informants with a list of common indigenous terms for severe mental disorder. These terms were gathered in 2 qualitative investigations preceding the main epidemiologic study.

Explanatory models concerning the source of mental disturbances may influence patterns of service utilization.25-28 For example, supernatural beliefs about psychosis may deter patients or their families from seeking medical care from conventional mental health services.23 Because the aim of the study was to assist in planning culturally appropriate services in Timor Leste, we included an assessment of these indigenous attributions.

Timor Leste is a half-island territory whose population was subjected to extensive human rights violations during the Indonesian occupation (1975-1999). Widespread conflict occurred in 1999 following a popular vote on independence.29 A United Nations force established peace in late 1999, and the country gained independence in 2002.

The country is mountainous with a limited road and transport network, making many villages inaccessible. In addition, at the time of the survey, there were no national census data available. For both these reasons, it was not feasible to undertake a nationally representative study. A further constraint was the absence of village maps in rural settings, making it likely that dwellings located in remote, mountainous terrain might be overlooked.

In early 2004, the government of Timor Leste selected 2 sites, thought to be broadly representative of the country, in order to undertake a pilot census as a preliminary step to conducting a nationwide census. In undertaking the East Timor Mental Health Epidemiologic Needs Survey (ETMHENS), we were able to access the aerial maps and global positioning system coordinates produced by the census team in order to identify all dwellings in the 2 study locations. The advantage was that we would not overlook remotely situated dwellings in the rural area.

The urban site studied is a densely populated suburb of Dili, the capital. The suburb is adjacent to the mountains, offering a strategic transit point for militants entering or leaving the city during the insurgency war (1975-1999). As a consequence, the suburb was the site of extensive military activity, repression, and violence. The rural site is situated beyond the mountains, approximately a 1-hour drive from the capital. Life in the village remains largely traditional with most persons involved in subsistence agriculture. Given the relative proximity to the city, the village was directly affected by conflict, with waves of displaced persons seeking temporary refuge there during the occupation and subsequent emergence of 1999.

### METHOD

#### AIMS AND OBJECTIVES

The study aimed to apply a novel method for identifying the range of clinical disorders relevant to planning mental health services in a low-income, postconflict country, Timor Leste.30 In addition, in phase 2, we assessed disability associated with mental disorder, local understandings of the origins of illness (explanatory models), and perceptions of service need.

#### POPULATION AND DESIGN

The pilot census divided the 2 study areas into enumeration tracts, 5 in the rural area and 8 in the urban area. Higher population density in the urban area resulted in the random selection of 1 tract in that location (667 adults in 181 households) and 4 tracts in the rural area (887 adults in 365 households).

There were no data available to guide sample size estimates for indigenously identified disorders in Timor Leste. We, therefore, drew on the postconflict literature that indicated that our intended sample (N > 1000) represented a large sample for studies in the field.

The design involved a 2-stage, whole-of-population survey of adults older than 18 years living in the designated population tracts. The key informant method sought to detect psychosis in members of each household by applying indigenous terms for mental disorders. Hence, to ensure coverage of the identical population, the separate screen for PTSD and depression was applied to all members of the same households. That design required assessment for household clustering on key outcome measures.

Phase 1 of the study involved 2 methods: (1) Application of standard screening instruments to the whole adult population to assess for PTSD and general indices of psychologic distress, including symptoms of depression and anxiety. Of those who screened positive, 50% were then randomly assigned to phase 2 clinical interviews. (2) In a separate procedure, we visited the same households participating in the aforementioned screen, presenting a list of indigenous terms for mental disorder to the household head or the most senior person present (“informant”). The informant identified household residents suffering from 1 or more of these conditions. All those identified then proceeded to phase 2 clinical interviews.

In phase 2, clinicians administered a structured diagnostic interview, as well as measures of disability and explanatory models. In situations in which the index person was threatening, family members were interviewed.
Screening measures were chosen because of their brevity and demonstrated psychometric properties. Because of low levels of literacy, the measures were administered verbally. We field-tested the measures in an adjacent rural district to ensure that they were comprehensible to the local society.

The Harvard Trauma Questionnaire (HTQ), used in 2 previous studies involving Timorese, was administered to assess PTSD. We applied the cutoff (score, 2.0) that in other transcultural studies has yielded high levels of sensitivity. The Kessler-10 instrument (K10) is a 10-item questionnaire that assesses psychologic distress, including symptoms of depression and anxiety. We applied the recommended cutoff (score, ≥30). Because the measure has been included in the WHO [World Health Organization] World Mental Health Surveys undertaken across multiple countries and culture, there is the potential to compare our findings with the results of those surveys when they are published in the future. The screen also included demographic data as recorded in the pilot census (age, sex, marital status, and educational level).

INDIGENOUS TERMS FOR MENTAL DISORDER USED

Phase 1

A previous qualitative study based on focus groups documented a range of indigenous terms for mental disorder (Psychosocial Recovery and Development in East Timor [PRADET], unpublished data, 2003). We reassessed these terms in a study undertaken in a village adjacent to the rural site identified for the future ETMHENS. We conducted individual interviews with the chiefs (“chelés”), other community leaders, and members of 30 households. Participants were requested to review the existing list of indigenous terms, suggesting further terms if necessary, and describing a person they knew who suffered from any of these conditions. No new terms were identified, with those on the established list receiving wide endorsement. The most commonly applied term was bulak, a generic state of “madness.” Affected persons spoke nonsense, shouted at others for no reason, spoke to themselves, threw stones indiscriminately, and acted in bizarre ways. Other terms (eg, bilan and hanoin barak, or “thinking too much”) represented less severe disorders. Some terms were characterized mainly by their assumed causes. For example, rai-nain was a disturbed state that followed the breaking of a taboo such as killing a crocodile or handling a sacred object. In other transcultural settings, it was not possible to identify clear boundaries among indigenous categories, with respondents often ascribing several terms to 1 person.

Phase 2

In phase 2, medical practitioners applied the Structured Clinical Interview for DSM-IV (SCID) modules for schizophrenia, bipolar disorder, psychotic disorder not otherwise specified, mood disorders, PTSD, and alcohol disorders (drug abuse was not an identified problem in the society at the time). Previous studies have supported the validity, inter-rater reliability, and test-retest reliability of the SCID. Because dating of illness onset and course proved difficult in a community that is less time conscious, we applied the point prevalence estimate. Small numbers required aggregation of major depressive episode and dysthymia into “depression.” Where there was comorbidity, clinicians assigned a primary diagnosis based on the effect of symptoms on personal suffering and disability.

DISABILITY

The DSM-IV–based Global Assessment of Functioning scale yields scores ranging from 0 (no functional ability) to 100 (fully functional). In addition, we selected an interviewer-rated version of the World Health Organization Short Disability Assessment Schedule (WHO DAS-S) for use in phase 2. The WHO DAS-S generates a global score based on ratings made on 4 domains of functioning: personal care, occupation, family, and household, and broader social contact. The measure has yielded sound psychometric properties in 2 multisite, international field trials.

EXPLANATORY MODEL INTERVIEW

The Short Explanatory Model Interview was modified according to the findings of the preceding qualitative study. Where respondents attributed the illness to multiple factors, we inquired into the primary cause, the index used in further analyses. Cultural explanations for illness were readily grouped post hoc into 4 categories: supernatural, physical, social, and arising from psychologic trauma. An example of a supernatural explanation is provided in Figure 1.

All measures were translated and back-translated into Indonesian and Tetun, the local language, using standard methods. Discrepancies were resolved by a panel of bilingual Timorese community workers.

PERSONNEL AND TRAINING

Twenty Timorese survey workers, all educated to secondary school level, carried out the phase 1 screening procedure. Training included simulated classroom interviews and supervised field trials in a village not earmarked for the main study. Four medical practitioners trained in England with postgraduate psychiatry experience, 2 with degrees in medical anthropology, provided on-site supervision and carried out the phase 2 interviews. They developed a working knowledge of Tetun, and 1 was fluent in Indonesian. Timorese interpreters were available at all phase 2 interviews.

ETHICS

The Human Research Ethics Committee of The University of New South Wales and the Timor Leste Ministry of Health approved the study, as did the chiefs of the villages. Because of the low levels of literacy, participants provided verbal consent.
STATISTICAL ANALYSIS

The age and sex distribution of the ETMHENS sample did not differ from the larger population covered by the pilot census, so that post-stratification adjustments were not needed. Low intraclass correlation coefficients (0.11 for HTQ; and 0.08 for K10) meant that statistical adjustment for household clustering was not required. Prevalence estimates were weighted for case-finding procedures and adjusted for participation rates. Because the study represented a small census area, confidence intervals were not calculated.

RESULTS

We identified 1544 adults living in 548 dwellings. Of the 1245 residents who agreed to participate (80.6% response rate), 500 (41.0%) resided in the urban area; 52.1% were women. The mean (SD) age of the whole sample was 33.3 (12.5) years and 68.2% were married. Most participants (74.0%) had completed 6 or fewer years of formal education.

PREVALENCE OF MENTAL DISORDER

Figure 2 outlines the cases yielded by the 2 methods used in Phase 1. Respondents reaching threshold scores on the screening measures are referred to as screen positives. Community-identified cases refer to those identified by household informants applying indigenous terms.

The phase 1 screen results are presented in the first column of Figure 3. Of the 1271 persons screened (82.3% response rate), 30 were also identified by the household informant method and they are included in the second column of Figure 3 to avoid duplication. For the screening procedure, column 1 (row 4) shows that 124 participants (10% of the screened population) scored above threshold on the K10 or the HTQ or both. We randomly selected 50% of screen positives (n=62) for interview in phase 2. Rows 5 and 6 show that of these, 54 (87.1%) were interviewed and 19 (35.2%) were assigned a diagnosis: schizophrenia (n=0), PTSD (n=8), major depression (n=8), and alcohol dependence (n=2). Additional notes kept by medical personnel indicated that 24 (44.4%) screen positives not assigned a DSM-IV diagnosis in phase 2 had either subthreshold symptoms or recently remitted symptoms, mainly of PTSD or major depressive episode.

The second column of Figure 3 shows the results for the household informant method. Thirty community identified cases were detected (1.94% of the total population) (row 2). Nineteen participated in interviews and for 4 persons, data were gathered from families. Of these, 21 were assigned a DSM-IV diagnosis (row 6): schizophrenia (n=4), bipolar disorder (n=2), psychotic disorder not otherwise specified (n=10), major depression (n=2), and alcohol dependence (n=3).

Hence, the phase 1 screen yielded a point prevalence of 12.0% (screen positives plus all community-identified cases), whereas the phase 2 clinical interviews, based on DSM-IV diagnoses, reduced the estimate to 5.1%.

PREVALENCE OF MAJOR DISORDER DOMAINS BASED ON THE SCID

Psychosis

The SCID identified 4 cases of schizophrenia, which, when adjusted for the number of interviews (23 of 30), yielded a point prevalence of 0.34% (3.4 cases per 1000). Adding other psychotic disorders (psychotic disorder not otherwise specified, 0.84%; and bipolar disorder, 0.17%), the estimated aggregated point prevalence for psychosis was 1.35% (13.5 cases per 1000), with all cases identified by the household informant method (Table 1).

Nonpsychotic Disorders

The adjusted point prevalence for PTSD based on the SCID was 1.47%. Adjusted rates for all nonpsychotic disorders based on the SCID (PTSD, major depressive episode, dysthymia, and alcohol dependence) was 3.72%, with 82.0% of cases identified by the phase 1 screen based on the HTQ and K10 (Table 1).

DISABILITY

Table 1 includes disability ratings for each mental disorder. Small numbers limited statistical testing to aggregated disorders only. A stepwise pattern emerged. Psychosis was most disabling, followed by nonpsychotic disorders and those who were screen positive but were
were SCID-negative tended to give social explanations. Those with nonpsychotic disorders tended to invoke so-
cial causes and psychologic trauma. Respondents who
tended to invoke supernatural causes associated with psychosis were supernatural.

EXPLANATORY MODELS

Almost all those with an SCID diagnosis (psychotic, 94%; and nonpsychotic, 87%) reported that the symptoms they were experiencing caused them substantial living difficulties. Figure 3 indicates that the most common attributions associated with psychosis were supernatural. Those with nonpsychotic disorders tended to invoke social causes and psychologic trauma. Respondents who were SCID-negative tended to give social explanations. Table 2 shows that only a few of those with an SCID diagnosis consulted a health professional, with psychotic patients consulting at twice the rate as those with nonpsychotic disorders. Most of those with psychosis (81%) but only a few with nonpsychotic conditions (22%) consulted a traditional healer. Nevertheless, more persons with nonpsychotic disorders expressed a desire for treatment by an outside agency.

COMMENT

We believe the ETMHENS represents the first epidemiologic study in a postconflict country to include an estimate of psychotic disorders. The 2 methods used in phase 1 proved to be complementary, with the screening instruments detecting the key nonpsychotic disorders (PTSD and depression) and the household informant method detecting mainly the psychotic disorders.

There is a consensus in the literature that applying brief self-report screening instruments tends to yield inaccurate estimates for low prevalence disorders such as psychosis. Hence, we applied a method that was not reliant on self-reports, namely, a household informant approach based on indigenous terms for mental disorder. The method detected a point prevalence for schizophrenia (3.4 per 1000) that fell between the 50th and 75th percentiles for low-income developing countries. The prevalence of broadly defined psychosis (including schizophrenia) (13.5 per 1000) was high compared with neigh-

Table 1. DSM-IV Prevalence Estimates, Efficiency of Case Identification Methods, and Associated Disability

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>No. of Cases</th>
<th>Population Prevalence per 1000</th>
<th>Household Informant (CIP)</th>
<th>Screen (SP)</th>
<th>GAFb Mean (SD)</th>
<th>WHO DAS-Sb Mean (SD)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Schizophrenia</td>
<td>4</td>
<td>3.4 (0.34)</td>
<td>100</td>
<td>1 (25.0)</td>
<td>26.3 (11.8)*</td>
<td>12.5 (4.4)%</td>
</tr>
<tr>
<td>Psychosis NOS</td>
<td>10</td>
<td>8.4 (0.84)</td>
<td>100</td>
<td>5 (50.0)</td>
<td>37.4 (15.1)*</td>
<td>8.5 (5.2)%</td>
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<tr>
<td>Bipolar disorder</td>
<td>2</td>
<td>1.7 (0.17)</td>
<td>100</td>
<td>0 (43.0)</td>
<td>35.0 (7.1)*</td>
<td>10.5 (3.5)%</td>
</tr>
<tr>
<td>All psychotic disordersc</td>
<td>16</td>
<td>13.5 (1.35)</td>
<td>100</td>
<td>6 (37.5)</td>
<td>34.1 (13.7)</td>
<td>9.8 (4.9)</td>
</tr>
<tr>
<td>Depression</td>
<td>10</td>
<td>16.4 (1.64)</td>
<td>20</td>
<td>9 (90.0)</td>
<td>59.6 (13.6)†</td>
<td>4.3 (2.6)†</td>
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<td>PTSD</td>
<td>8</td>
<td>14.7 (1.47)</td>
<td>0</td>
<td>8 (100.0)</td>
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<td>Alcohol</td>
<td>5</td>
<td>6.2 (0.62)</td>
<td>60</td>
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<td>No SCID diagnosis</td>
<td>38</td>
<td>NA</td>
<td>5</td>
<td>36 (94.8)</td>
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Abbreviations: CIP, community-identified person; GAF, Global Assessment of Functioning scale; NA, not applicable; NOS, not otherwise specified; PTSD, posttraumatic stress disorder; SCID, Structured Clinical Interview for DSM-IV; SD, standard deviation; SP, screen positives; WHO DAS-S, World Health Organization Short Disability Assessment Schedule. The same superscript footnote symbol (*, †, §, ||, ¶, and #) indicates that the categories are the same; different superscript letters, a significant difference between the categories using least significant difference post hoc analysis.

a Numbers for each case finding approach are not mutually exclusive.
b The GAF and the WHO DAS-S are scored in opposite directions. The higher the GAF score, the less disability; the higher the WHO DAS-S score, the greater the disability.
c Combines schizophrenia, psychoses, and bipolar disorder.
d Combines depression, PTSD, and alcohol disorders.

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boring Australia (5.5 per 1000) (calculated from tables provided by Jablensky et al44). These high rates may be accounted for by several factors: the greater efficiency of the case identification method compared with conventional low prevalence approaches, an accumulation of untreated persons in Timor Leste, and the inclusion of reactive psychoses and/or culture-bound syndromes.45-49

Psychosis was associated with severe disability: in 4 of the cases we identified, families reported periods when they had to apply physical restraints to the person. Our findings, therefore, argue against the previously held belief that psychotic disorders are more benign in developing countries.50,51 The evidence presented instead supports calls for more services to be established for psychosis in these settings.9,15,52,53

We recorded a low rate of bipolar disorder compared with other settings (indicative range, 0.5%54,55 to 3.0%56,57). Several factors may have accounted for this discrepancy. We may not have identified the appropriate indigenous term for this disorder, challenges in cross-cultural assessment may have resulted in some identified people being allocated to the psychotic disorder not otherwise specified group, and some identified people may have been in remission at the time of the survey.

Supernatural attributions may influence whether persons with psychosis attend conventional mental health services.58 As in Africa,23 such attributions were common in our study. This factor may have accounted for the high rates of consultation with traditional healers by those with psychosis. The data suggest, therefore, that cultural beliefs about illness may need to be considered when designing services for conditions such as psychosis in transcultural settings such as Timor Leste.

The prevalence estimates for PTSD (7.0% based on the screen; 1.47% for the SCID) were low compared with other postconflict settings,7 particularly in contrast to the rate (34%) reported by a study, also using the HTQ, conducted in the immediate aftermath of the 1999 emergency in Timor Leste.8 Sampling differences may account for some of the variation in rates yielded across these studies. It is also possible that the conditions of peace that prevailed in the intervening 4 years (preceding the present study) played an important role in allowing acute PTSD symptoms to remit in many members of the population.6,17,59 At the same time, as our data show, there is a risk that the few persons who experience persistent PTSD may not receive the treatment they need in low-resource countries such as Timor Leste.

Strengths and limitations of the study need to be acknowledged. We were able to achieve a high response rate for both methods used in phase 1. Nevertheless, resource constraints prevented us from assessing for possible false negatives by interviewing a random sub-sample of those who did not reach cutoff scores on the HTQ or K10. We used the community cutoff for the HTQ, a threshold that in other cultures has achieved a high level of sensitivity, limiting the rate of false negatives.33 Furthermore, in phase 2, we found that screen positives not assigned an SCID diagnosis had high rates of subthreshold disorders or partially remitted disorders almost all related to PTSD or depression. These findings make it unlikely that a significant number of full cases of PTSD or depression were overlooked by the phase 1 screen. We could not estimate how many persons with nonpsychotic disorders refused to participate. Transcultural error is always possible in translating measures and in undertaking interviews. We did not assess other disorders relevant to these settings, particularly neuropsychiatric conditions.

In summary, the method used appears feasible and effective in producing epidemiologic data of value to planning services in a transcultural, postconflict setting. The level of unmet need was evident. In 2005, the entire East Timor National Mental Health Program,30 responsible for a country of 1 million persons, consisted of 1 psychiatrist, 1 administrative officer, and 15 mental health workers, each with a caseload of approximately 100 patients. More than half the time of 1 of those workers would be needed to attend to the persons with mental disorders identified in the present study, a subgroup derived from a base population of just more than 1500 persons.

The ETMHENS applied a novel approach that proved effective and feasible in identifying low (psychosis) and high (PTSD and depression) prevalence disorders in a postconflict country. The phase 2 clinical interviews proved valuable in refining diagnostic assignments. The explanatory model assessment added information concerning indigenous beliefs about the causes of illness, data that may guide the design of culturally sensitive services. The point prevalence estimate of 5.1%, including highly disabling psychotic disorders, poses a major challenge for provid-

Table 2. Beliefs and Help-Seeking Behavior by Diagnostic Group

<table>
<thead>
<tr>
<th>Diagnosis</th>
<th>Believe They Have a Problem</th>
<th>Health Professional</th>
<th>Healer</th>
<th>Believe They Can Be Treated</th>
<th>Total</th>
</tr>
</thead>
<tbody>
<tr>
<td>Psychotic illness</td>
<td>15 (94)</td>
<td>4 (25)</td>
<td>13 (81)</td>
<td>6 (38)</td>
<td>16 (100)</td>
</tr>
<tr>
<td>Nonpsychotic illness</td>
<td>20 (87)</td>
<td>3 (13)</td>
<td>5 (22)</td>
<td>12 (52)</td>
<td>23 (100)</td>
</tr>
<tr>
<td>No diagnosis</td>
<td>11 (31)</td>
<td>2 (6)</td>
<td>1 (3)</td>
<td>3 (9)</td>
<td>35* (100)</td>
</tr>
</tbody>
</table>

* Three patients did not provide responses regarding help-seeking behavior.
ing adequate services in postconflict, resource-poor countries such as Timor Leste.

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