

**Indices of social risk amongst first attenders of an emergency mental health service
in postconflict East Timor: an exploratory investigation**

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Indices of extreme social risk amongst first attenders of an emergency mental health service in postconflict East Timor.

Objective: Little is known about the profile of patients treated in mental health services in low-income, postconflict countries, especially in the post-emergency phase. We postulated that patients attending the first community mental health service in East Timor would be characterized not only by mental disturbance but by high levels of social vulnerability.

Method: Drawing on existing methods and on consultations with East Timorese mental health staff, five social indicators were identified: dangerousness; inability to undertake life sustaining self-care; bizarre behaviour; incapacitating distress; and social unmanageability. Adequate levels of inter-rater reliability (65%-91%) were achieved in identifying these indicators from case notes. Forty eight randomly selected case notes were analysed to ascertain the prevalence of social risk factors as well as the referral source and broad diagnostic groupings.

Results: Major referral sources were the family, humanitarian agencies and the police. Twenty nine percent met criteria for dangerousness; 42% for inability to undertake self-care; 58% for bizarre behaviour; 75% for distress and 19% for unmanageability. Ninety-eight percent fulfilled at least one social indicator, with the modal score being 2.

Conclusions: Although the approach to documentation and analysis was preliminary, the data suggest that a focus on social risk indicators may assist in determining those mentally disturbed persons in need of priority care in resource-poor postconflict countries.

Key words: humanitarian emergencies; postconflict; trauma; community mental health; war; East Timor

Serious questions have been raised about the legitimacy of importing Western-based mental health services into traditional societies recovering from war and mass conflict [1]. Some authorities have claimed that violence-affected communities have effective indigenous healing methods that attend to psychological reactions without need for external assistance [2]. Yet other observations suggest that some severely mentally ill persons are at great risk of abuse and neglect in postconflict settings in the developing world [3, 4]. Much of the conjecture about needs is based on anecdotal and theoretical observations, with relatively few reports [5] providing systematic descriptions of newly established mental health services in postconflict countries, particularly in the immediate post-emergency phase. The establishment of PRADET (Psychosocial Recovery and Development in East Timor) [6], the first community mental health service established in that country after the humanitarian emergency of 1999, provided an opportunity to assess social vulnerabilities of patients given priority attention.

Years of mass conflict and underdevelopment in East Timor left the territory without any mental health professionals or specialist services at the time of the emergency in 1999 [7]. The risk was that, as in other postconflict settings[3], the treatment needs of the severely mentally ill might be neglected and that bizarre or disruptive behaviours exhibited by a minority of such persons might undermine the capacity of carer families to focus effectively on pressing survival needs. In such settings there is an additional risk that the mentally ill will be institutionalised in poorly staffed and monitored facilities [4], or alternately, incarcerated in prisons, resulting in their abuse and neglect. In the community as a whole, the socio-economic costs associated with the

undertreatment of the mentally ill in post-conflict countries may be substantial [8], although this issue has not been sufficiently investigated.

East Timor is one of the least developed countries worldwide, with poverty being endemic and many health problems (communicable diseases, maternal-infant health problems, malnutrition) receiving inadequate attention [7, 9]. By 1999, the society had been disrupted by 24 years of persecution involving massacres, torture, extra-judicial killings, scorched earth policies and mass internal displacements [10-12]. Following the referendum on independence in 1999, militia groups embarked on a rampage across East Timor in which 80% of the built infrastructure of the country was damaged or destroyed, and 70% of the population was displaced.

Torture and trauma services have worked with East Timorese refugees and asylum seekers in Australia for many years [13]. In 1999, a national grouping formed PRADET to plan a program for psychosocial recovery and development in East Timor [6]. Supported by AusAID, Australia's overseas development agency, and the New South Wales Department of Health, PRADET recruited and trained a group of 15 community mental health workers, most of whom were general nurses. The new team established a national psychosocial resource centre in the capital, Dili, where local personnel were supported by two Australian staff and volunteers [6]. Day clinics were established in and around the capital, domiciliary care was offered to outlying villages, a consultation service was developed with the jail, the hospital and other humanitarian agencies, and a mobile outreach service was extended to the distant districts with the support of the United Nations High Commissioner for Refugees. Visiting psychiatrists and other mental health professionals provided short-term consultancy to the service.

The project was guided by an evolving set of principles focusing on social survival and adaptation [14] with the emphasis being on providing emergency and ongoing care to individuals and families at risk of social incapacity or danger. The model was entirely community-based, providing domiciliary care to patients in a manner that aimed to reduce stigma, normalize distress, and mobilize family and community supports. In parallel, there was a strong emphasis on capacity building by training, supervising and mentoring East Timorese personnel. Over time, efforts were directed towards assisting the emerging government and Ministry of Health in the planning and organization of a national mental health strategy, work that is ongoing.

Conservative estimates in Western countries [15] indicate that 2 to 3% of the population are in immediate need of psychiatric assistance. Epidemiological data from postconflict settings suggest that much greater numbers (between 15 and 47%) [16-18] suffer from traumatic stress disorders. For example, Modvig and colleagues [16] recorded a PTSD rate of 34% in East Timor soon after the emergency in 1999. Doubts have been raised, however, whether such epidemiological data provide an accurate estimate of the actual need for immediate services amongst postconflict populations [19]. Given the limitations in skills, resources and infrastructure in East Timor, the challenge for PRADET was to ensure that, from the large pool of potential cases [20], we focused on those at extreme social risk.

Aims

The aim of the present review of PRADET case notes was to investigate the level of social risk manifested by early patients attending the service. The purpose was to

explore in a preliminary manner whether early referrals were characterized by social vulnerabilities that would impede sufferers and their families from adapting to the demanding postconflict context of East Timor at the time.

Method

Rating of social indicators

Working within the context of a developed country, Slade and colleagues [20] have developed a method for identifying the social indicators of extreme need amongst those with severe mental disorder. The seven indicators identified include intentional and unintentional self-harm; risk from and to others; survival; psychological and social disability; and distress. We aimed to modify and simplify the approach to ensure that the indicators identified matched the East Timor context.

In the first step, the second author (VM) met with 15 East Timorese community mental health workers as a group to review the domains identified by Slade and coworkers. Based on their collective experience, consensus was reached in reducing the original seven indicators to five: danger to self or others; inability to undertake life-sustaining self-care; bizarre behaviour; incapacitating distress; and social unmanageability. Workers then conferred to identify operational criteria for each domain based on their own experience of referral patterns. The consensus-based criteria that emerged were: 1. For self-harm and danger: immediate threat of self-harm or danger to others reflected in violent acts, behaviours or imminent threat; 2. for incapacity in self-care: evidence of failure in at least one domain: to eat unassisted, to get out of bed, to dress or toilet independently; 3. bizarre behaviour: extreme, culturally inappropriate behaviour that was highly provocative to family or community such as throwing stones, screaming at

night, or walking about naked; 4. incapacitating distress as manifested by crying, acting persistently sad or agitated to the extent that overt expressions of distress severely interfered with the person's family or work roles; and 5. unmanageability: the person's mental incapacity was so severe that the family and/or other caregivers could not provide adequate care and protection.

Data Source

East Timorese mental health workers had received intensive training in case note documentation prior to the commencement of the PRADET service. Ongoing training aimed to achieve a degree of standardization across workers in recording notes. The visiting mental health specialists (psychiatrists, medical practitioners) undertook an independent systematic history and that documentation was added to the workers' case notes. Hence, although case notes were not fully structured, extensive data were available in each file.

Once criteria for identifying the five social risk indicators were established, a random subsample of 23 case notes were rated independently by VM and one of the visiting doctors. Inter-rater agreement was achieved in 74% of cases for dangerousness, in 78% for incapacity, in 65% for bizarre behaviour, in 78% for distress, and in 91% for unmanageability.

Psychiatric diagnoses

Provisional clinical diagnoses based on DSM-IV were recorded first in the case notes by East Timorese workers and then reviewed by psychiatrists. Structured clinical interviews were not feasible given the early stage of development of the service and the transcultural context.

The preliminary review of 23 case notes revealed that psychiatrists were sensitive to the risk of transcultural error, applying provisional, broad diagnostic categories that left open the possibility of more definitive diagnoses being made over time. For example, although psychosis was readily identified, it was not always possible in early assessments to allocate cases with certainty to subcategories such as brief psychosis, schizophrenia or the manic phase of bipolar disorder. For the non-psychotic disorders, substantial comorbidity was evident across the broad categories of depression, anxiety and PTSD and several cases were regarded as suffering adjustment disorders. Hence for the present review, broad categories of psychosis, affective disturbance (depression, anxiety, PTSD) and adjustment disorder were applied in analysing the case notes.

Case note review

VM then randomly selected 48 case notes (not used in the pilot study) of the first 100 patients seen by PRADET, and assigned ratings on each of the identified indicators. Demographic, diagnostic and treatment variables were also recorded.

Results

Twenty-five (52%) were male and the average age of the whole sample was 33 years. Twenty-one (48%) were diagnosed with a psychotic disorder, the most common provisional category being schizophrenia. Affective disorders (depression, anxiety, PTSD) accounted for 13 cases (27%), neuro-organic disorders including head injury and epilepsy for 2 cases, and the remaining 10 (21%) were categorized as adjustment disorders. The most common sources of referral were the family (40%), humanitarian agencies (UN officers or NGOs) (19%), and the police (18%).

Twenty nine percent of the sample were rated as behaving dangerously, 42% as unable to undertake life sustaining self-care, 58% as showing bizarre behaviour, 75% as manifesting incapacitating distress, and 19% were socially unmanageable. Ninety-eight percent fulfilled at least one social indicator, with the modal score across all patients being 2.

Seventy-seven percent received psychotropic medication, 95% were given some form of counselling including family education and support, 31% were referred to a primary care clinic for medical complaints, and 8% to other agencies for assistance with housing, welfare and other forms of support.

Discussion

Our experience in East Timor supports other observations in postconflict settings internationally [4] suggesting that there is a portion of psychiatrically disturbed persons who need urgent care from mental health services in the aftermath of humanitarian emergencies. That need is likely to be magnified in severely disrupted postconflict environments which, by their very nature, undermine the capacity of families to support mentally disturbed members who are dysfunctional or disruptive.

Newly established services in low-income, postconflict settings are challenged by extensive unmet needs but limited skills and resources. It is clear that the patients treated by PRADET only represented a small percentage of the expected number of persons with psychiatric disturbances in the community [16]. Analysis of referrals indicated that the range of disorders treated was wide, with the broad categories of psychosis, affective and adjustment disorders being well represented. Given the novelty

of the transcultural context for the psychiatrists, the provisional broad diagnostic groupings used seemed appropriately cautious, with definitive diagnoses being reserved until further observation had occurred.

The pilot study indicated that of the patients able to access the service, almost all met criteria for one extreme social risk indicator, with the modal score being two. The criteria identified related to overt manifestations of danger, threat and incapacity at a level that interfered with the essential functions of the family, caretakers or the broader community. As such, there seemed little doubt that the patients receiving attention faced major challenges to survival and adaptation in the disrupted and impoverished environment prevailing in East Timor following the upheavals of 1999. Importantly, their incapacity was likely to have a multiplier effect in reducing the ability of families and, at times, the wider community, to attend to the taxing task of survival and reconstruction. Since there was no comparison group studied in the community however, we cannot estimate how many mentally disturbed persons with equivalent levels of social need were not treated by the service.

The findings need to be regarded as preliminary given the limitations of documentation and measurement. Although inter-rater reliability for each social indicator varied, agreement was adequate overall. Nevertheless, the constraints of the circumstances and resources did not allow extensive psychometric testing of the rating system such as has been undertaken by Slade and colleagues [20] in a developed country. Further studies will be needed therefore to test the robustness of the social indicators identified in this exploratory investigation.

The study was also dependent on the accuracy and completeness of case notes. Although the training of workers aimed to achieve standardisation in note taking, there is always a risk that workers varied in the quality and detail of their documentation. Nevertheless, visiting psychiatrists added their own full assessment to each of the case notes, providing a second source of information about the reasons for referral.

Conclusions

Limits in the methodology caution against definitive conclusions being drawn, but the results presented herein do provide tentative support for previous clinical observations [3] suggesting that where mental health services are established in postconflict settings, families, aid agencies, the police and other key institutions tend to identify and refer persons at great social risk. The indicators of dangerousness, incapacity, bizarre behaviour, disabling distress, and unmanageability appeared to characterize well the state of social urgency associated with early referrals to PRADET, since almost all patients met one indicator, with the modal score being 2. Given ongoing controversies about the relevance of mental health interventions in these environments [3, 4], urgency of social need arising from mental disturbance of any cause may provide a point of consensus in guiding priorities for mental health service development in postconflict settings.

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