Epidemiological assessment in emergency settings: recommendations for enhancing a potentially useful tool

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The authors identify several factors that have limited the utility of epidemiological assessments in emergency settings, such as a narrow focus on post traumatic stress disorder (PTSD), an inattention to cultural variations in distress, and a failure to distinguish between normal distress reactions and actual disorder. Rather than rejecting epidemiology altogether, however, as the Inter-Agency Standing Committee (IASC) Guidelines on Mental Health and Psychosocial Support in Emergency Settings do, recommendations are made for ways to enhance the usefulness of large scale mental health and psychosocial assessments in settings of armed conflict and natural disaster.

Keywords: Inter-Agency Standing Committee (IASC), guidelines, epidemiology, conflict, disaster, psychosocial, mental health

The recently published *IASC Guidelines on Mental Health and Psychosocial Support in Emergency Settings* takes a bold and provocative stance to the conducting of large scale epidemiological assessments of mental disorders in populations that have been affected by organized violence and/or natural disaster. In recognizing the potential utility of epidemiological assessments in the *'general population'*, the guidelines adopt the view that such assessments are inappropriate in emergency settings, primarily *'because they have generally been poorly conducted to date'*. They suggest that in most epidemiological studies in war and disaster affected populations:

(1) There has been a narrow focus on assessing symptoms of posttraumatic stress disorder (PTSD) without consideration of its validity or utility in specific cultural contexts;
(2) Minimal attention has been paid to culturally specific indicators and idioms of distress;
(3) There has been a heavy reliance on measures developed in Western cultural contexts without adequate (or sometimes any) standardization for use in specific non Western settings; and
(4) Researchers have failed to distinguish between normal distress reactions, on the one hand, and actual mental disorders, on the other hand. This has led to overestimating the prevalence of actual disorder and inappropriately viewing all expressions of distress as psychopathology requiring clinical intervention.

Moreover, the guidelines suggest that large scale assessments are too time intensive to be useful in emergency situations.

We are in agreement with all these criticisms, with the exception of the last point. In our

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view, epidemiological assessments of mental and psychosocial wellbeing in emergency settings have generally been flawed for all of the reasons cited. We concur that an assessments' tendency to focus narrowly on the effects of direct exposure to violence and natural disaster, while failing to consider other sources of *ongoing* stress, such as domestic violence, social isolation, and poverty, is an important limitation. All of these sources may also mediate or exacerbate the impact of organized violence and disaster. We also agree with the guidelines that, as a result of these limitations, epidemiological studies in settings of war and natural disaster have too often poorly served organizations seeking to develop effective mental health and psychosocial interventions, as well as policy makers trying to set funding priorities.

However, we respectfully disagree with the *conclusion* reached by the authors. Dismissing any role for epidemiology solely because it has been poorly conducted in the past ignores the important role that well conducted population based surveys can play in the development of culturally sound, empirically based interventions tailored to the specific needs of particular populations. Population based surveys can identify the nature and intensity of mental health and psychosocial needs, the determinants of those needs, and the resources available or needed to promote healing and adaptation. Rather than *'throw the baby out with the bathwater'*, we advocate a new look at how epidemiological studies can be conducted, so as to be genuinely useful to practitioners and policy makers alike.

In the remainder of the paper, we offer several recommendations for ways to enhance the usefulness of large scale mental health and psychosocial assessments in settings of organized violence and natural disaster.

Recommendation 1) Transcend the narrow focus on post traumatic stress disorder (PTSD) to include a broader range of outcomes, including locally salient indicators and idioms of distress

There has been a widely held assumption that PTSD should be the primary focus of mental health assessments in complex emergencies (Barenbaum et al., 2004; de Jong, 2002; Miller et al., 2006). The assumption seems be based on three premises: (1) war and natural disasters are inherently terrifying and life threatening, that is, potentially *traumatic*; (2) PTSD is *the* universal post trauma syndrome; and (3) other outcomes, such as grief, depression, and various indigenous expressions of distress are less relevant than PTSD from a clinical point of view. There is, in fact, no empirically sound rationale for these assumptions. It is true that war and disaster entail exposure to frightening and destructive events. However, complex emergencies do a great deal more than expose people to traumatic stress:

- They result in the devastation of social networks, leading to isolation and loneliness;
- They cause the meaningless deaths of loved ones, generating intense grief and in some cases depression;
- They force the reorganization of families when breadwinners or caretakers are disabled or killed, increasing the risk of family conflict and forcing children to take on adult roles prematurely;
- They destroy homes and livelihoods, thereby worsening poverty related stressors;
- They transform children into orphans, who may then be at increased risk of abuse and neglect; and
- In situations of armed conflict, they often lead to the use of child soldiers, who are forced to commit heinous

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violence and often face the daunting task of reintegration into the very communities against which they have committed abuses.

To reduce this complex set of consequences into a single outcome, PTSD, strikes us as peculiar, and of limited utility to practitioners trying to develop effective interventions.

Furthermore, the assumption that PTSD is the most useful way of encapsulating post trauma reactions, regardless of the cultural context, is simply not supported by the available data. Most measures of trauma developed in the west focus on intra psychic symptoms. However, in many cultures, emotional distress may be more clearly expressed in interpersonal and social relationships.

Moreover, although it is true that several symptoms of PTSD are found in diverse cultures, it is also clear that culturally specific posttrauma symptoms and syndromes exist that are distinct from PTSD. Such indicators and idioms of distress are much more familiar to people in non-western settings than western psychiatric categories such as PTSD, even though respondents may endorse particular items on a PTSD scale. We know less about culturally specific post trauma syndromes than we do about PTSD, not because they don't exist, but because we have generally neglected to ask about them.

One need only ask Guatemalan Indians or rural Salvadorans about the impact of state terror in order to hear descriptions of *susto*, *nervios*, and *calor*; syndromes that arise in the wake of traumatic stress, and that overlap only modestly with PTSD. *Susto*, *ataque de nervios*, and *calor* are syndromes indigenous to Latin America that all reflect enduring, distressing reactions to frightening, potentially traumatic experiences. Although they are distinct syndromes, they all entail a combination of physical and psychological symptoms of distress (eg. feelings of panic in *aquae de nervious* and an intense sensation of heat cursing through the body in *calor*) and may significantly impair psychosocial functioning. Ask an Afghan about the psychological impact of war, and you'll likely hear about *jigar khun*, *fishar*, and *asabi*. These are the terms that Afghans use to describe their suffering, and they are not merely Dari equivalents of PTSD symptoms, any more than *susto* and *calor* are Spanish synonyms for PTSD.

A familiarity with culturally specific indicators of distress is essential to the conduct of useful epidemiological assessments. To assess only symptoms and syndromes that are culturally unfamiliar is simply not useful to NGOs wishing to develop culturally appropriate mental health and psychosocial services.

However, a useful method for identifying local indicators and idioms of distress has been described by various authors, including Bolten & Tang (2002), Fernando (in press), Hart, et al. (2007), and Miller, et al. (2006a). Free listing techniques, in which people are asked to generate words or phrases related to a specific topic, are used to elicit common indicators of distress or impaired functioning. These can then be used directly as items on questionnaires or grouped into meaningful categories (i.e., using a pile sort). Questionnaires that include these locally salient items can then be used, either alone or together with conventional measures of distress (i.e., PTSD, depression) in large scale assessments. This approach was used to create the Afghan Symptom Checklist (ASCL) (Miller, et al., 2006b) that includes several items not typically assessed by western psychiatric questionnaires. In two surveys of

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mental health in Kabul, the ASCL was used to identify particularly vulnerable groups, and to identify the relative salience of different indicators of distress. Importantly, *jigar khun*, which translates roughly as *heartbreak*, was a more enduring and subjectively more distressing expression of distress than symptoms of PTSD. It was, in effect, persistent *grief* much more than the western psychiatric construct of trauma that most troubled Afghanis.

A similar approach was used in Sri Lanka (Fernando, in press), where focus groups, key informant interviews, and free listing were used to identify key indicators of well-being and distress, as well as psychosocial functioning in adults. The resulting Sri Lankan Index of Psychosocial Status for adults (SLIPSS-A) was then used in a countrywide survey to identify the mental health and psychosocial needs of people affected by the war and the tsunami. In this study, PTSD was also assessed. Although PTSD symptoms were present, other types of distress were considerably more salient. When funding is scarce and decisions need to be made to fund one type of intervention programme over another, the focus on PTSD and PTSD related interventions may benefit only a small proportion of the community and fail to address mental health concerns deemed by community members to be of greater salience.

Recommendation 2) Assess the impact of ongoing stressors other than direct exposure to war and disaster that also impact mental health and psychosocial wellbeing

There is a small, but growing body, of research showing that much of the variance in mental health status in situations of complex emergencies is due, not to previously experienced violence and loss (i.e., direct exposure to war related violence or natural disaster), but to *ongoing* stressors in people's environment. These are the stressful conditions of everyday life in war zones or settings of natural disaster. We have mentioned several such stressors already: social isolation, unemployment, poverty, and child abuse. Other stressors include: intimate partner violence, sexual assault within refugee camps, and lack of access to adequate housing and health care. Far too often, epidemiological studies have focused narrowly on the impact of direct exposure to war and natural disaster, while failing to consider the profound effects that *'daily stressors'* may have on mental health and psychosocial wellbeing.

Although we can, and should, try to ameliorate the long term effects of exposure to war and disaster related traumatic stress, we cannot undo the reality of these events - they have already occurred. However, we *can* target ongoing stressors to change them once we have identified them. Community centres, shared rituals and events, and various types of social programmes can reduce isolation and increase the availability of social support. Poverty reduction programmes (e.g., micro-enterprise) can also significantly reduce poverty related stress, while preventive and ameliorative interventions can be designed to address problems such as domestic violence and sexual assault.

Recommendation 3) Distinguish between normal stress responses and actual clinical disorder

There is a reason that the DSM IV-TR specifically cautions against diagnosing PTSD within a month of exposure to traumatic stress: most people get better, as their symptoms of traumatic stress resolve naturally. In our view, it is neither useful nor ethical to draw any conclusions about the number of cases of PTSD or *'probable PTSD'* in a population in the immediate aftermath of trauma exposure (Neuner et al., 2006). It can be helpful to know about

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levels of different types of distress in the immediate aftermath of disaster, but such knowledge should have as its aim the promotion of supportive resources that facilitate naturally occurring processes of recovery. Strong social support and the re-establishment of safety and predictability are more likely to facilitate a return to normal functioning than any sort of clinical intervention, which is best reserved for those individuals who continue showing distress long after the traumatic stressors have ended and a natural healing period has transpired.

Recommendation 4) Take appropriate steps to validate assessment tools in specific contexts

It is neither difficult, nor time consuming, to create culturally grounded assessment tools as described above. However, there may also be value in using measures shown to be useful in other cultural contexts than only in the setting in which one is working. Simple steps can be taken to validate existing measures. For example, focus groups can be conducted to ensure the meaningfulness, ease of understanding, and cultural appropriateness of all items on measures developed in another culture, and an expert panel can also review these items. Local experts (i.e., teachers, community leaders, etc.) can be asked to identify high and low functioning (or minimally versus highly distressed) individuals, and scores for these two groups on assessment measures can be compared to test their discriminant validity. Scores on questionnaires can also be compared to clinical diagnosis, although we caution that high levels of agreement between the questionnaire based assessment of western diagnostic constructs and interview based assessment of those same constructs speak only to the capacity of the questionnaires to measure particular diagnostic entities, and not to the *meaningfulness* or *utility* of those diagnoses in particular cultural contexts. For example, scores on a measure of PTSD may correlate highly with a psychiatrist's interview based diagnosis of PTSD; however, this does not necessarily indicate that PTSD is a meaningful construct in that setting, only that it exists, and that the measure does a good job of assessing its presence.

Importantly, clinical cut-offs developed in one cultural context should never be used to establish whether someone meets diagnostic criteria for a disorder in epidemiological surveys conducted in different cultural contexts – a surprisingly common practice. Clinical cut-offs are based on specific populations, and they lack meaning or validity when used outside of those populations. It has unfortunately become commonplace for researchers to acknowledge that it is problematic to use to cut-off scores based on other populations than wherever they happen to be working, but to then go ahead and use those clinical cut-offs anyway. If it is problematic, it's probably best to not do it.

Recommendation 5) Epidemiological assessments should be linked to the development of mental health and psychosocial resources. There is little value in simply documenting the well established truth that war and disaster are bad for mental health.

This point requires little elaboration. Epidemiological studies that provide useful data to NGOs and policy makers are, in our view, well justified. However, the increasingly common practice of entering a complex emergency and expending considerable resources merely to document that a lot of people have been exposed to traumatic stress and show elevated levels of distress seems to us of questionable value (Lopez Cardozo et al., 2004). Let us take it as established that war and disaster are bad for mental health. Before embarking on any sort of epidemiological assessment

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in a complex emergency, we would urge researchers to identify clearly how and by whom their findings will be used. If this cannot be done, then the assessment itself is likely to be of limited utility, no matter how well conducted.

Concluding comments

Thoughtfully conducted epidemiological surveys can yield data that are highly useful to policy makers and practitioners alike. Such studies do not require enormous resources; indeed, small teams of trained surveyors can gather a great deal of information in a matter of days, using culturally grounded assessment tools that can also be rapidly developed. The critical question is not whether such assessments can be done efficiently, or whether they have the potential to be highly useful; they can and do. The key issue is whether researchers working in complex emergencies are willing to take needed steps to better ensure that their efforts are maximally beneficial to NGOs and policy makers addressing the mental health and psychosocial needs of affected communities.

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