Author's response to reviews

Title: Mental, neurological, and substance use problems among refugees in primary health care: analysis of the Health Information System in 90 refugee camps

Authors:

Jeremy C Kane (jkane29@jhu.edu)
Peter Ventevogel (ventevog@unhcr.org)
Paul Spiegel (spiegel@unhcr.org)
Judith K Bass (jbass1@jhu.edu)
Mark van Ommeren (vanommerenm@who.int)
Wietse A Tol (wtol1@jhu.edu)

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Department of Mental Health
Johns Hopkins Bloomberg School of Public Health
8th Floor
624 N. Broadway
Baltimore, MD 21205

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Sabina Alam, PhD
Editor, *BMC Medicine*

Dear Dr. Alam,

Thank you for the opportunity to revise our manuscript titled, “Mental, neurological, and substance use problems among refugees in primary health care: analysis of the Health Information System in 90 refugee camps.” Note that the attached manuscript has used track changes in Microsoft Word in order to enhance the reviewers’ ability to assess the modifications we have made. Please let me know if you would like us to send a ‘clean’ version of the manuscript as well.

We would also like to thank the reviewers for their thorough, helpful and generally positive review of our submission. We have carefully revised our manuscript following the recommendations outlined in their review. Below please find a point-by-point response that specifies how we have addressed the Editor comments as well as each of the two reviewer comments.

Thank you again for the supportive review and your further consideration of publication in *BMC Medicine*.

Sincerely,

Jeremy C. Kane, MPH
Doctoral Candidate, Johns Hopkins Bloomberg School of Public Health
Authors' responses to reviewer comments are in Bold.

Editor Comments

1. Please ensure your manuscript conforms to the journal style.

The two tables have now been uploaded separately as “Additional Files” because they are in Landscape view and exceed the size requirement for regular tables.

Reviewer Comments

Reviewer 1:

1. In the results section of the abstract when you say that 211,728 MNS visits were reported, are you referring to visits to seek treatment for MSN? Or visits for whatever reason by people with MSN?

   This refers to the number of visits specifically for treatment of MNS problems not visits for whatever reason by persons with MNS problems. We have clarified the language in the results section of the abstract to read: “A total of 211,728 visits for MNS problems were reported”. Although it is possible that the visit to the clinic included care for another type of health problem in addition to the MNS, we do not have data on this.

2. You speak in the results section of the abstract of the “visit rate” for epilepsy/seizure. It would be better to refer to this as the “proportion of all MNS visits,” as the term “visit rate” implies that you’re telling us about the proportion of people in the population of refugees with epilepsy/seizure who seek treatment. The last sentence of this section states it more accurately, although you should again refer to percent “of MNS visits,” not to percent “of visits” and you should clarify if by the latter term you mean visits for the primary purpose of seeking help for an MNS. I assume the latter is so, as it’s implausible to think that epilepsy/seizure disorder is the most commonly occurring MNS among refugees. If that’s the case, though, then you need to be clearer in the background section of the abstract in making sure readers recognize that the term “MNS visits” means visits in which patients seek help for MNS rather than for rates of MNS among patients. The latter is almost certainly a great deal higher than the former. This distinction is made more clearly in the Conclusions section of the abstract, but it would help the reader follow the logic if it was made more clearly from the very beginning.

We thank the reviewer for this suggestion and we have clarified the wording of the abstract so that we consistently refer to “percent of MNS visits” as opposed to “percent of visits”. We have also modified the Background section of the abstract so as not to imply that this is the rate of service use among those with MNS problems.
In this paper we are reporting two types of statistics,

1) the proportion of MNS visits attributable to each of the 7 MNS categories (e.g., epilepsy/seizure), which allows us to measure which MNS categories are responsible for more clinic visits relative to other MNS categories, and

2) the rate of visits for MNS problems (both overall and for each of the 7 categories) which allows us to compare the actual rate of visits for MNS problems across countries, age groups, and by sex. Two countries may have a similar proportion of visits attributable to one of the categories, while the rates of visits (as visits per population) might be quite different. For example, both Liberia and Yemen have approximately 15% of MNS visits attributable to epilepsy. The rate of epilepsy visits in Liberia, however, was 3.7/1,000 persons/month and the rate in Yemen was 0.72. In order to avoid confusion among readers we refer to the calculation of visit rates as “contact coverage”, or the proportion of individuals in the target population who are in contact with services, as described by De Silva et al (2014). We have added this explanation and citation to the Methods, pages 8-9.

Of course, contact coverage of a problem is very different to actual prevalence of these problems in the refugee camps. Rather, this provides an indication of health service utilization, or ‘contact prevalence’ (De Silva et al 2014). We do not infer that community prevalence rates of epilepsy would be higher than rates of depression, PTSD, or any other MNS problem among refugees, but rather that rates of visits to primary healthcare clinics for epilepsy are higher than rates of visits to primary healthcare clinics for other types of MNS problems. As we write in the Discussion and illustrate in Figure 1, there are a number of possible reasons for the relatively higher rates of epilepsy visits as compared to other MNS problem visits including help-seeking behavior, recognizability and treatability of the problem, and quality of services.

We have clarified that there were two types of statistics reported in the Methods section of the abstract. In the Results section of the abstract we have clarified throughout when we are reporting the visit rates vs. the proportion of visits attributable to one of the 7 categories. We have also clarified this in the Methods section, pages 8-9 in the description of our analysis.

3. The first para implies that the adversities experienced by refugees cause psychosis and epilepsy. Does evidence for this causal claim exist? Is this claim needed? Even in the absence of such causal effects, we would expect 1-2% of refugees to have psychotic disorders simply because that’s the prevalence in the general population.
Epilepsy and psychotic disorders among refugees are conditions that are typically pre-existing and not directly related to adversities they have experienced (although there is some literature to show that they may have a higher risk of epilepsy due to brain injury, infection and poor nutrition, which we discuss in para 3, page 5 of the Background). We thank the reviewer for catching this. We have removed the phrase “as well as severe neuropsychiatric disorders such as psychosis and epilepsy” from that paragraph. We now structure the Background such that paragraph 1 focuses on common mental disorders such as depression, anxiety, and PTSD and paragraph 2 focuses on psychotic and neurological disorders.

4. The para beginning at the bottom of page 4 and ending at the top of page 5: The conclusion of this para strikes me as controversial. Do we really care about the reason for presenting if we discover that there are what we consider more fundamental underlying issues that need to be addresses? If someone with psychosis presents because of a broken arm sustained when the px jumped off a roof in an attempt to fly, wouldn’t we focus on the psychosis as well as the broken arm? Ditto with the issue addressed in this passage of the text. It’s good to know, of course, what problems patients seek help for, but the fact that only a small proportion of the people with PTSD seek help – possibly because they don’t conceptualize their PTSD sxs as “illnesses” that can be treated by doctor – should not mean that PTSD should not be a focus of clinical attention. I know this is not what you were trying to say, but you need to take care in framing the research question to avoid that interpretation on the part of the reader

We agree with the reviewer’s sentiment: “the fact that only a small proportion of the people with PTSD seek help – possibly because they don’t conceptualize their PTSD sxs as “illnesses” that can be treated by doctor – should not mean that PTSD should not be a focus of clinical attention.” In fact, the other side of the coin of this argument partly informed these analyses: if there turns out to be a large discrepancy between prevalence rates from rigorous epidemiological research in refugee populations and the types of problems that actually reach health clinics, then this should inform more proactive behavior on behalf of service providers to inform community members of the options for treatment of highly prevalent disorders at clinics (we state this in the concluding paragraph of the manuscript, page 16).

In framing our research question we intended to highlight the utility of service use data for MNS problems, particularly that 1) discrepancies in service use data with prevalence data (e.g., with PTSD) may indicate a substantial treatment gap that warrants attention (as the reviewer points out) and 2) service use data might reveal that there are types of MNS problems among refugees (e.g., epilepsy) for which we do not have as much prevalence data but indicate that rates of visits to healthcare centers are high, warranting attention and perhaps increased resource allocation
and/or capacity building so that we are able to successfully match the high number of visits for a particular problem with the appropriate clinical response. We have reworked the concluding sentence to this paragraph (para 5, page 6) to reflect both of these.

We have also changed the language in the first sentence of paragraph 5 so as not to emphasize the importance of a problem a client is “presenting” with, but rather the importance of measuring the number and type of MNS problems that are treated in the clinic.

5. The 5th para in the discussion section: You say that your findings of high treatment rates of epilepsy and psychotic disorders RELATIVE TO other MNS confirm previous findings of high rates of severe mental and neurological dxs in humanitarian settings. That’s incorrect. All you did was look at proportions WITHIN MNS visits. Let’s say there were only 10 MNS visits per 1 million total visits but that 9 out of the 10 were for epilepsy or psychosis. This would show that the PROPORTION of MNS visits that occur due to epilepsy/psychosis is high but that the ABSOLUTE NUMBER (i.e., 9/1 million total visits) is extremely low. You focused on the former comparison, not the latter, so you can’t make the claim you do in this paragraph.

The reviewer is correct to point out that the relative number of epilepsy visits (compared to visits for other MNS problems) was high while the absolute number was low. We again emphasize that in this study we have measured contact coverage in this study and not community prevalence. We have removed the phrase in paragraph 5 (pages 12-13) which compares our findings to the high levels of severe mental and neurological disorders in humanitarian settings from previous studies. We continue to note in this paragraph, however, that previous studies have similarly found higher rates of service use for epilepsy and psychotic disorders relative to other MNS problems among refugees to provide context to our findings. As we state in the final sentence of this paragraph (page 13), we believe the relatively high contact coverage of services for epilepsy and psychotic disorders found in our study relative to other MNS problems is an important finding given the relatively few studies in the refugee literature devoted to the measurement of and treatment for epilepsy and psychotic disorders.

6. I must say that I was disappointed with the remained of the section after the 5th paragraph, as your interpretation seems to leave us nowhere. You’ve shown that very few people in these settings seek help for common mental dxs. Yet we know from other research that such disorders are highly prevalent among refugees. What do we conclude from that? You seem to be concluding that epidemiologists have got it all wrong because people in these settings don’t seek help for common mental dxs. They seek help mostly for epilepsy and psychosis. But what about the possibility that this pattern of help-seeking
indicates that there is a massive problem of unmet need for treatment of common mental disorders in refugee populations? Sure, we will always have people coming in for treatment if they have very severe problems like a seizure disorder or active psychosis. Treatment providers need to recognize this and be prepared to help those severe cases. But the fact that the vastly larger number of people with more common mental disorders fails to seek help strikes me as a major problem. Why doesn’t this seem to strike you as a problem? The discussion of this issue strikes me a wildly off base and needing a complete rethinking.

We thank the reviewer for the comment but would disagree with this characterization of our interpretation of the findings. We do not believe that epidemiologists have gotten it all wrong. We proposed the Figure 1 conceptual framework in an effort to elucidate why the relative rates of visits for MNS problems (contact coverage) differed from relative population rates of MNS problems themselves in epidemiological research. Reasons we hypothesized for this included help-seeking behavior, accessibility of services, and quality of providers.

We are not arguing that the population estimates for common mental disorders from epidemiological studies are inaccurate; in fact we have no way of measuring prevalence of disorders in our study. We simply want to highlight that the epidemiological literature on refugee mental health could benefit from a broader focus that would include psychotic disorders and other severe mental disorders given what appears in our data to be a higher degree of contact coverage for these disorders relative to other MNS problems. We consider it a key finding that the relative visit rates for psychosis and epilepsy were high compared to other MNS problems. As we state in the conclusion (page 15), we believe the finding supports calls for more attention to quality care of people with these types of morbidities in refugee settings and for future research to include methods to measure their incidence and prevalence.

We do agree that an important part of this story is the low rate of service use for common mental disorders. We also agree that this is a significant problem that suggests a possible treatment gap.

We noted in the Conclusions section of the Abstract: “Relatively low rates of identified emotional and substance use visits compared to high population-based rates from other studies suggest that many MNS problems remain unattended by refugee health services.”

We regret that this point was not made clearly enough in the manuscript itself.

Therefore we have now explicitly mentioned this as one of our main findings in the discussion section on page 13: “Conversely, the fifth major finding is that service use
for emotional disorders, such as depression, anxiety disorders and PTSD, is low, relative to psychotic disorders and epilepsy as well as in absolute terms. The health care system in the refugee camps seems not to cater adequately for people with emotional disorders.”

We also added reference to this in the Conclusion section of the Discussion, page 16.

Reviewer 2:

1. This is a well-written report on a very valuable data base collected between 2009-2013 on neuropsychiatric disorders among refugees and internally displaced persons (IDPs). The report presents differences in primary care visits for different disorders as well as differences by nation, age and gender. All of this will be of great interest to readers. I recognize that acquiring such a massive data set is a major undertaking for which the authors are to be congratulated

We thank the reviewer for his supportive and encouraging review.

2. There is no good discussion of the rationale for the case definition categories shown in Table 1. “Severe emotional disorder,” for example, appears to encompass mood, anxiety & trauma-related disorders. Furthermore “other psychological complaint” might or might not encompass some DSM/ICD psychiatric diagnoses. I think that readers want to know why a more recognizable diagnostic classification was not utilized. I am not, necessarily, criticizing the scheme that was adopted but stating that more attention needs to be devoted to explaining the rationale and limitations of this approach.

We thank the reviewer for these pertinent remarks, as the seven categories in the UNHCRs Health Information System may not be self-explanatory. We have adapted the text as follows (Methods section, pages 7-8):

“Seven MNS categories were developed in a consultative process with key experts from the World Health Organization and UN agencies and international non-governmental organizations active in mental health service delivery in humanitarian emergencies. The seven categories present a modification of the categories proposed in the Inter-Agency Standing Committee (IASC) Guidelines on Mental Health and Psychosocial Support in Emergency Settings (MHPSS) (Inter-Agency Standing Committee, 2007). The seven categories were comprised of: 1) epilepsy/seizures; 2) alcohol/substance use disorder; 3) mental retardation/intellectual disability; 4) psychotic disorder; 5) severe emotional disorder; 6) medically unexplained somatic complaint; and 7) other psychological complaint. Case definitions for each category were developed to suggest probable diagnosis in a primary health care setting (Table 1). These categories were designed to include MNS problems relevant to primary care in refugee settings, keeping in mind that a limited number of categories would enable feasible
implementation. Among the consulted experts there was consensus to make a
distinction between ‘severe emotional disorders’ (such as severe and disabling forms of
depression and posttraumatic stress disorder) that need to be prioritized within the
health care system and ‘other psychological complaints’ that would include less severe
forms of depressive and anxiety disorders, as well as strong emotional reactions such
as acute stress reactions and grief reaction that are common in emergency settings and
that may or may not be pathological.”

3. Because of the classification scheme that was adopted, there is no way to interpret the
current findings within the diagnostic context mentioned in Introduction (where most of
the literature is about PTSD and depression among refugee and IDP populations).
Epilepsy is another example. Given the distinction between “fits” (seizures) and “spells”
(non-organic seizures) and the finding that the latter are often preceded by a traumatic
event, it would be useful to address this issue. Again, there are inherent limitations to the
potential granularity of archival data. They should be acknowledged and discussed in the
paper.

We agree that there are limitations to the classification scheme (discussed in point 2
above) as it does not match neatly onto the DSM and ICD classification systems that
are meant for mental health professionals while the UNHCR system is made for
general health care settings. We have acknowledged these limitations and discussed
them further in the Discussion limitations section, page 15.