Author’s response to reviews

Title: Persistent Mental and Physical Health Impact of Exposure to the September 11, 2001 World Trade Center Attacks

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Version: 1 Date: 04 Jan 2019

Author’s response to reviews:

Reviewer #1: This article reports the results of a survey conducted by the WTC Registry among responders to the 9/11 attack and residents in lower Manhattan.

The manuscript is well written with methods clearly described and results adequately reported.

1. The discussion should remark the main limitation of self reported data, and comment on potential divergence from objectively collected health data in this population.

Authors’ response:

We added a paragraph acknowledging this limitation to the discussion section.

2. More in details:
In 'Data source and study sample' please indicate the exact time period of enrollment in Wave 1
Authors’ response:
We added the time period (September 5, 2003-November 20, 2004) to the methods section.

3. In '9/11-related exposures', the definition of 'Personally witnessing a traumatic event' does not include visual of physical contact with human remains. Please explain why.
Authors’ response:
That specific exposure was not included in the enrollment questionnaire. However, the exposure to human remains was studied in a sub-sample of Registry participants who participated in clean-up activities (Fairclough et al., Relationship between persistent post-traumatic stress disorder and human remains exposure for Staten Island barge and landfill recovery and clean-up workers after 9/11. International Journal of Emergency Mental Health and Human Resilience, 17:661-663.)

4. On page 8, line 9 please clarify who are the 'non participants' to Wave 4: subjects enrolled in Wave 1 but not participating in Wave 4?
Authors’ response:
We changed the sentence to read, “We assessed whether Wave 4 participants differed from those who enrolled at Wave 1 but did not complete Wave 4…”

5. On page 10, line 20-24 - clarify where are the data supporting the statement "Among rescue/recovery workers, the prevalence increased with longer duration of work and earlier date of arrival for work’?" Authors’ response:
This refers to results that are shown toward the bottom of table 1. To increase clarity, the wording of this sentence now reads, “Among rescue/recovery workers, the prevalence of asthma was higher among those with longer compared to shorter duration of work, and higher among those who had initiated rescue/recovery work on or soon after 9/11 than in those who began participating in rescue-recovery work later.”

6. Data are not reported also for other observed dose/duration-responses
Authors’ response:

The dose-response relationship was not as clear for other health outcomes, so we did not remark upon them in text, although they are shown in tables 1 and 2.

7. In the discussion, page 13, line 48, the estimate of 162,000 individuals possibly affected by 9/11 conditions seems much larger than the number of individuals attending the WTC clinical centers for treatment. Please comment on this apparent discrepancy.

Authors’ response:

The WTC health program reported that approximately 90,000 persons had enrolled in the program as of September 2018 (https://www.cdc.gov/wtc/ataglance.html#enrollmentWTC). This is lower than our estimate of persons who have developed 9/11-related health conditions. The difference may be attributable to several factors. A substantial component of the Registry are persons who were passersby or visitors on 9/11, and therefore may not be eligible for the World Trade Center Health Program. Additionally, the Health Program estimate includes only persons who have sought some sort of medical evaluation through the program, and it is quite likely that many 9/11-exposed persons have either not sought care for their conditions, or have sought care outside the WTC Health Program. Consistent with this, the WTC Health Program report cited above shows that several hundred new members joined the program each month during 2018, suggesting that there is a large pool of persons who are either not aware of or not interested in seeking care through the program. Furthermore, Registry enrollees continue to report barriers to seeking care (Petrusic et al. Considerations for future disaster registries: effectiveness of treatment referral outreach in addressing long-term unmet 9/11 disaster needs. Disaster Prevention and Management, 27:321-333. Welch et al. Translating research into action: an evaluation of the World Trade Center Health Registry’s Treatment Referral Program. Disaster Health. 2:97-105)

8. On page 14 please report also the age-adjusted lifetime prevalence of asthma reported in the 2015 National Health Interview Survey and the 2014 New York City Community Health Survey

Authors’ response:

We added the estimates to the sentence.

9. On page 15, line 46, please briefly explain what is the 'Registry's Treatment Referral Program''
Reviewer #2: In this study the authors aimed to investigate the long-term effects of the September 11, 2001 World Trade Center Attacks on certain physical and mental health variables along with health-related quality of life in a large cohort. This article is of importance because it has the potential of furthering the knowledge and understanding of the long-term consequences of World Trade Center Attacks. This topic may be of interest for publication, but certain flaws reduce enthusiasm for this manuscript. Below are my comments.

1. The authors used self-rating questionnaires (‘PTSD Checklist’ and ‘Patient Health Questionnaire’) to evaluate PTSD and depression symptoms, which is the main shortcoming of the study.

Authors’ response:

We acknowledge that self-completed screening questionnaires have limitations. We employed them not as a substitute for clinical evaluations, but rather a method of assessing the mental health needs of a panel of nearly 37,000 participants. These screening tools have been used extensively to assess the mental health needs of large populations and cohorts, including multiple previous studies of 9/11-exposed persons as well as national and local health surveys, thus enabling comparison to general population rates. We agree it is essential that persons with mental health symptoms have the opportunity to be assessed clinically and to obtain treatment, if needed. In the discussion section of the revised manuscript, we elaborated further on the limitations of these tools.

2. Screening instruments fail to assess all criteria for the diagnosis of PTSD, including establishing exposure to a traumatic event, differentiating new from pre-disaster symptoms, determining duration of symptoms, and demonstrating the clinical or functional significance of the symptoms. PTSD symptom tool does not specifically anchor the symptoms in a qualifying disaster trauma exposure.

Authors’ response:

We agree that the PCL-17 tool that we used to assess PTSD does not assess duration of symptoms, and therefore we did not attempt to report on duration of symptoms in this manuscript. Regarding establishment of exposure to 9/11, potential enrollees were only accepted into the Registry if they reported substantial, direct exposure to 9/11 or the subsequent rescue
and recovery efforts. Furthermore, the Registry uses an event-specific version of the PCL-17 tool that refers specifically to 9/11. This version of the event-specific PCL-17 has been used in multiple previous Registry studies and in studies of other 9/11-exposed cohorts. In the revised manuscript, we explained that the version of the PCL-17 was event-specific in the methods section.

3. Applying the concept of "probable PTSD" may inflate estimates of PTSD and overdiagnose individual cases.

Authors’ response:

While it is possible that “probable PTSD” may over-estimate clinician-diagnosed PTSD, our aim was to provide information on the burden of this condition and to assess the current level of unmet need for mental health care among 9/11-exposed persons. We believe that the clarifications that we have added to the paper, including the discussion of the limitations of self-reported data and of screening tools, will help make this clearer to readers. It is also important to consider that clinically diagnosed PTSD may underestimate the full burden of PTSD, because not all persons with PTSD seek care or receive a diagnosis. In support of this, our study found that access to mental health care is sub-optimal, even for this group of persons who are entitled to care through a federally funded health program.

4. Self-report questionnaires, such as PHQ, do not perform well as diagnostic tools for depression at any cutoff.

Authors’ response:

We agree that the PHQ is not a substitute for a clinical assessment of depression. Similar to our rationale for using the PCL-17, we used the PHQ because it is a validated tool that is suited to use on questionnaires, thereby enabling the assessment of the level of depression, and the degree of need for mental health care, in a large cohort. We believe that the enhanced discussion of the limitations of our study methods addresses this concern.

5. Employing self-report methods to diagnose asthma and GER might lead to inflated prevalence of these conditions, as well.

Authors’ response:

We have added a paragraph on the limitations of self-reported data to the discussion section.
6. What was the participation rate in the registry? Can the authors provide some estimate of the participation rate in the registry sample? If this is a nonrepresentative sample, the limitations section of the manuscript should discuss this limitation.

Authors’ response:

The Registry is a voluntary study that attempted to enroll as many directly exposed persons as possible. Those who were exposed to the 9/11 attacks were not enumerated, so it is unknown exactly how many persons were exposed. It is estimated, however, that the Registry enrolled approximately 17% of those who were eligible (Murphy et al. Measuring and maximizing coverage in the World Trade Center Health Registry. Stat Med. 2007;26:1688-701), and that coverage of rescue-recovery workers was higher than coverage of area residents, workers, or passers-by. We added this limitation in the discussion section.

7. The authors assume that the problems (including physical symptoms) observed after the 9/11 WTC attacks are caused by the 9/11 WTC attacks. The design of this study does not allow drawing causal associations.

Authors’ response:

We agree that the present study was not designed to study causation, although multiple other studies have established strong connections between the conditions that we included in our analysis. To clarify this, we removed or qualified references to “9/11-related conditions” when reporting our results.