Author's response to reviews

Title: A qualitative examination of health and health care utilization after the September 11th terror attacks among World Trade Center Health Registry enrollees

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Version: 2 Date: 7 June 2012

Author's response to reviews: see over
Dear Miss Pafitis,

Thank you for sending our manuscript, entitled “A qualitative examination of health and health care utilization after the September 11th terror attacks among World Trade Center Health Registry enrollees” out for review. The reviewer’s comments were most helpful and the authors have significantly revised the manuscript accordingly. Please find our response to the point-by-point critiques below. In the manuscript, our edits are highlighted in grey.

**Minor revisions**

1. There are differences in how the purpose of the study is presented in title, abstract, and research questions

   a. Clearly spell out a coherent research question that is reflected in all areas of the manuscript.

   The authors have addressed the differences in how the purpose of the study is presented in the title, abstract, and research questions by editing the background section of the manuscript to be more in line with the title and abstract (background, page 6, paragraph 1). A coherent research question is now reflected in all areas of the manuscript.

   b. Clearly articulate the gap in current knowledge that will be filled by this study. It appears that a lot of literature exists already in relationship to the questions that the authors intend to address. What is the specific novel element?

   The specific novel element of this study is that it was conducted among those directly exposed to the WTC disaster and focuses on utilization of 9/11 specialty healthcare. The literature on post-9/11 healthcare utilization is limited to broad based samples of NYC residents and does not focus on the use of WTC specialty care. As such, little is known about the use of 9/11-related specialty care among those directly exposed to the disaster. The gap in current knowledge that we aim to fill with this study is now more clearly articulated in the manuscript (background, page 6, paragraph 1).

2. Attributions of causality (9/11 vs. aging vs current illness) related to the health problems may differ across individuals but also the real underlying causes may differ. Did the authors ask about the duration, onset, patterns of illness? It is reasonable to assume that 9 years + post 9/11 that the causes for illness are as varied as 1 yr post 9/11. Perhaps, aging-related concerns are the ‘correct’ attributions and consequently, not seeking care under the EHC provision is quite appropriate?
The authors recognize that attributions of causality (i.e. 9/11 vs. aging vs. current illness) related to health symptoms and problems may differ across individuals and that the underlying causes may also differ. The authors did not inquire about the duration, onset, or patterns of illness during the focus groups; however this information is gathered on our surveys.

There is a substantial body of literature that has clearly established a link between 9/11 exposures and physical and mental health outcomes (See Brackbill et al., 2009 and Perlman et al., 2011). However, it is reasonable to assume that the causes for illnesses are varied at both 1 year or 9 years post-9/11. Thus, aging-related concerns may be ‘correct’ attributions and not seeking care at a 9/11 program would be appropriate in some cases. It is our recommendation that symptomatic 9/11 survivors receive screenings for conditions that may be related to the events of 9/11. This is now more clearly articulated in the manuscript (discussion, page 15, paragraph 2).

3. For the international readership, spell out the relationship between the health care coverage provided under the EHC and other health insurance available to NYC citizens, including public and private payers. What about dual eligibility? Is for some WTC coverage the only coverage, while for others in the sample a mix of Medicare plus Private or solely Private is an option? Is EHC completely free or is copayment required? Describe the scope of the service and its interface with other services.

The manuscript now contains a more detailed explanation of healthcare charges for 9/11 services for persons with and without insurance, as well as a description of the insurance status of EHC patients in 2009 and screening services provided at the EHC (background, page 5, paragraph 2). We are unable to comment on the health insurance status of the focus group participants, as we did not obtain that information. We also provided a brief description of the payment structure for care at the EHC (background, page 5, paragraph 2).

4. The authors state that only a small proportion of people eligible under the WTC Registry provision accesses EHC services. Can they provide any details about the characteristics of the sample of people who seek access?

Information on the characteristics of persons who access EHC services is not publicly available. As described in our response to Minor Revision #3, we did provide information as to the insurance status of EHC patients. WTCHR data on utilization of the EHC were collected in 2006-2007 when the program was just beginning and therefore do not accurately reflect utilization at the time of the focus groups, which were held in January 2010.

5. The discussion mostly highlights the confirmatory character of the study, i.e. supporting findings from the literature.
The authors have revised the discussion section in order to provide a more nuanced argument. Additionally, the authors have built upon their recommendations for future WTCHR activities and research directions.

6. The authors derived some recommendations for practice from their findings. However, from the presented data is not clear how these recommendations have come about. For example, did they ask about preferred information channels and formats and how consistent were the use within as well as between groups?

The authors did inquire about preferred information channels and formats during the focus groups. However, the focus group recommendations were very broad and encompassed many information channels that have already been utilized by the WTCHR. As such, we did not include this information in the manuscript.

7. Provide additional literature about the service coordination between primary care provider and specialist services.

To address this concern we described some of the benefits of receiving care from a 9/11 specialist (background, page 5, paragraph 1). We also elaborated and included another citation on the primary provider-specialist relationship (discussion, page 14, paragraph 1).

8. Is additional research needed? If so, which questions remain to be answered?

Further research regarding primary care provider knowledge and attitudes towards 9/11 health and healthcare services is needed in order to optimize linkages between primary and specialty care and to inform future healthcare practices. This is now clearly stated in the manuscript (discussion, page 14, paragraph 2).

**Major revisions**

1. Provide a clear description of the chosen design and sampling strategy (e.g. purposive, maximum likelihood) as well as of inclusion/exclusion criteria.

The authors clarified that they used stratified random sampling in order that each group represented a particular group of WTCHR enrollees who were eligible for care at the EHC (methods, page 6, paragraph 1). The inclusion/exclusion criteria are also clearly stated in the methods section (methods, page 6, paragraph 1).

2. Provide a bit more detail about the focus group procedure.

The manuscript now contains more details about the focus group procedures (as stated below).

a. Was the moderator trained?
All focus groups were conducted by a trained and highly experienced moderator (methods, page 7, paragraph 1).

b. Where were the focus groups conducted?

The focus groups were conducted in New York City in January 2010 (methods, page 6, paragraph 1).

c. How long did the focus groups on average take?

The focus groups lasted approximately 90 to 120 minutes (methods, page 7, paragraph 1).

3. Provide more details on the data analysis based on the grounded theory by Glaser and Strauss. Typically this involves several steps of coding and it is not quite evident from the description how this was done in the present study. Also give some indication of how many codes were identified which were then reduced to the themes presented. Moreover, GT is typically used to explain (i.e. generate theoretical propositions) the relationship between different themes and topics. This is not done in the present study. Why was GT used and how was it used? Please provide a rationale for the choice of this approach.

The authors used thematic analysis as the analytic framework for their analysis in order to identify themes relevant to participants’ post-9/11 health and healthcare utilization (methods, qualitative analysis, page 7, paragraph 1). We originally described our work as using grounded theory (GT) because we applied the thematic coding process used within GT and cited GT as the framework. We recognize that we did not fully adhere to GT as we did not generate theoretical propositions based on our findings. As such, we revised our paper to more accurately represent our approach.

A total of 15 codes were identified based on initial content review of the focus group transcripts. These 15 codes were then further categorized into one of four themes: symptoms (physical symptoms and mental symptoms), barriers to care (logistical barriers, evidence, provider relationships, provider dismissal, and stigma), not connecting symptoms to 9/11 (aging, 9/11 symptom attribution, and time since 9/11), and program knowledge and utilization (attitudes, knowledge, utilization, sources of information, and WTC EHC). Information on focus group codes and themes is now clearly stated in the manuscript (methods, thematic analysis, page 8, paragraph 1).

4. What was done to ensure credibility, trustworthiness and transferrability of findings (e.g. member checks, inter-rater coding).

To ensure credibility and trustworthiness of findings, after all focus group transcripts were inductively open-coded, four of the authors met to review coded data and discuss and resolve discrepancies by mutual agreement (methods, qualitative analysis, page 7, paragraph 1).
5. The findings are mostly descriptive, which is acceptable but also somewhat limiting; sample contains substantial comparative potential to compare the experiences of subgroups, not only those based on the criteria used for producing the focus group samples but in addition those including age, gender, income, education, and health insurance status or payer type (uninsured, Medicaid, Medicare, Private) would be quite interesting. Moreover, the way their routine health care is organised (e.g. primary care gatekeeper, specialist access) may play a role in how likely they are accessing EHC services.

The authors are in agreement that this would be an interesting addition to the manuscript. However, specific individuals were not personally identified in the transcripts and no demographic characteristics could be associated with individual comments. Additionally, we did not collect information about their insurance status or health care organization and therefore cannot analyze the findings in this manner. This is now articulated in the manuscript (methods, page 7, paragraph 1).

6. One of the themes was labelled 'not connecting symptoms to 9/11'. This category likely includes a mix of true attributions as well as false attributions. What are the implications?

The authors acknowledge that ‘not connecting symptoms to 9/11’ likely includes a mix of true as well as false attributions. While it is possible that some health conditions may be caused by factors unrelated to the events of 9/11, symptomatic 9/11 survivors should be encouraged to receive screenings at 9/11 programs to ensure that they are receiving accurate diagnoses and optimal healthcare. This comment was addressed along with Minor Revision #2 and is now stated in the discussion section of the manuscript (discussion, page 15, paragraph 2).

7. There is no clear differentiation between knowledge and attitudes in relation to utilisation. Please clarify.

The authors agree that there was not a clear differentiation between program knowledge and attitudes in relation to healthcare utilization. We have removed the term ‘attitudes’ from the manuscript and now refer to 9/11 program knowledge and utilization.

8. Please provide more information about intra group variability as well as comparisons across different economic, income, and gender groups.

Given the small overall sample size (n=48) and the even smaller sizes of each of the six focus groups (8 to 12 participants), we are not able to provide information on intra-group variability or comparisons across different economic, income, or gender groups, as this could potentially violate human subjects confidentiality. Also, see response to Major Revision #5 above.

**Discretionary revisions**
1. As the analysis mostly remains descriptive some very interesting ideas may have gotten lost. For example, different cultural views of illness and its controllability. It would be fascinating to expand on this, especially since some of the respondents are native Spanish or Mandarin speakers. These views may inform attributions of symptoms.

The authors agree that different cultural views of illnesses and its controllability may inform attributions of symptoms. However, a cultural analysis is beyond the scope of the current manuscript.

2. Similarly, the issue of stigma, especially related to mental health services remains rather superficial and not sufficiently contextualised in existing literature.

The issue of stigma related to mental health services appears to be an important factor in our population and therefore warrants addressing in this paper, particularly as we make recommendations for outreach and education. We recognize that we performed a cursory review of the stigma associated with mental illness. We feel that stigma is a complex problem and an in-depth review would have been beyond the scope of this paper.