STUDY PROTOCOL

Systematic Review of Community-Based Responses to Epidemic and Pandemic Diseases

Study Team:
*Dr. Sharon Abramowitz, Department of Anthropology & Center for African Studies, University of Florida, USA
Ms. Kristen McLean, Department of Anthropology, Yale University, USA
Ms. Chelsea Lutz, Department of Epidemiology, University of Florida, USA
Ms. Amara Fazal, AmeriCorps NPRC, American Red Cross, USA

*Sharon Abramowitz takes responsibility for initiating, managing, and sponsoring the review. At present, there have been no unique identification numbers assigned.

Study Questions

- What common terms are used to describe “community-based response” to epidemics and pandemics in the social science, public health, and medical literatures?
- Which epidemics/pandemics have the most information about community-based responses? Which have the least?
- What kinds of community-based responses have been documented during epidemic and pandemic disease outbreaks?
- Which responses are supportive of public health interventions and containment measures; or are regarded as having halted or contained the epidemic or pandemic?
- Which responses are seen as “resistant to” public health and containment measures; or are seen as having contributed to the spread of the epidemic or pandemic?
- What common features of community-based response to epidemics can be identified in high-income vs. low- and middle-income (LIMC) countries?
- What kinds of literature and knowledge gaps exist about community-based responses to epidemics and pandemics?

Search Strategy

We will search the following electronic bibliographic databases: PubMed and EBSCOHOST. The search strategy will only include terms relating to or describing community-based responses to the following diseases: Avian influenza, cholera, SARS, hendra, hepatitis a, b, e, meningitis, viral hemorrhagic fever [dengue, Ebola, Marburg, lassa, Crimean-congo], nipah, tularaemia, human monkeypox, leptospirosis, rift valley fever, coronavirus, plague, bubonic plague, polio, and yellow fever.

Due to the novel and recent status of much of this literature, ‘grey literature’ resources from the additional sources will be sought out using a network of referrals: eg. WHO reports, World Bank reports, policy briefs, NGO reports, qualitative studies used for needs assessments, monitoring, and evaluation, case studies, newspapers, and news magazines.
Literature reviewed will be restricted to English language publications, to human studies, and to studies published between January 1964 and March 13, 2015. There will be no restriction placed on geographic origin.

Studies describing non-human interactions with epidemic or pandemic diseases, laboratory studies, virological, microbiology, or clinical research studies will be excluded. Studies only making incidental reference to an epidemic or pandemic, or otherwise off-topic will be excluded. In order to keep the literature to a manageable size, this study excludes research on HIV, AIDS, and Hepatitis C.

Searches will be re-run before the final analysis, and further studies retrieved for inclusion.

(((social or culture or cultural or community or local or response))) AND ((avian influenza or cholera or SARS or hendra or hepatitis a or hepatitis b or hepatitis e or viral haemorrhagic fever or dengue or meningitis or ebola or marburg or lassa or crimean-congo or leptospirosis or rift valley fever or plague or nipah or smallpox or human monkeypox or tularaemia or coronavirus or bubonic plague or polio or yellow fever)) AND (ethnography or systematic review or survey or focus group or participant observation or knowledge attitudes practices or KAP or interview or PRA or participatory rural appraisal or monitoring or evaluation or observation or longitudinal or intervention or cross-section or literature review or meta analysis or grounded theory or life history or key informant)

**Domain of Study**

Community responses to the following epidemic and pandemic diseases will be studied: Avian influenza, cholera, SARS, hendra, hepatitis a, b, e, meningitis, viral hemorrhagic fever [dengue, Ebola, Marburg, lassa, Crimean-congo], nipah, tularaemia, human monkeypox, leptospirosis, rift valley fever, coronavirus, plague, bubonic plague, polio, and yellow fever.

**Population**

Studies will include populations of humans, or those describing human-animal interaction, in the context of an epidemic or pandemic disease.

**Interventions/Exposures**

This is a systematic review of the medical, public health, and social science literature on community-based responses to epidemics and pandemics, and epidemic and pandemic responses.

We have focused upon epidemics and pandemics that are routinely monitored by the World Health Organization’s Global Outbreak Alert Network, including Avian influenza, cholera, SARS, hendra, hepatitis a, b, e, meningitis, viral hemorrhagic fever [dengue, Ebola, Marburg, lassa, Crimean-congo], nipah, tularaemia, human monkeypox, leptospirosis, rift valley fever, coronavirus, plague, bubonic plague, polio, and yellow fever. This subset of diseases is regarded as being both acute and timely in the current global health and biosecurity context.

In order to identify the general class of studies encompassed under the concept of community-based responses, we are using this systematic literature review process to iteratively construct a “concept map” of the term community-based response. Currently, we have included the following
terms: SOCIAL or CULTURE or CULTURAL or COMMUNITY or LOCAL or RESPONSE -- that would suggest community-based response. The final concept map will be included at the time of publication.

In order to capture the genre of methodologies that includes naturalistic, ethnographic, case study, qualitative, or community-based clinical trial interventions on this subject, we have also broadly defined a subset of methodological terms: ETHNOGRAPHY or SYSTEMATIC REVIEW or SURVEY or FOCUS GROUP or PARTICIPANT OBSERVATION or KNOWLEDGE ATTITUDES PRACTICES or KAP or INTERVIEW or PRA or PARTICIPATORY RURAL APPRAISAL or MONITORING or EVALUATION or OBSERVATION or LONGITUDINAL or INTERVENTION or CROSS-SECTION or LITERATURE REVIEW or META ANALYSIS or GROUNDED THEORY or LIFE HISTORY or KEY INFORMANT.

Study Designs Included

The following study designs will be included in the review: ethnography, survey, focus group, key informant interviews, interviews, systematic review, non-systematic review, literature review, historical/life history, participant observation, KAP surveys, PRA, grounded theory, monitoring and evaluation, community interventions [longitudinal or cross-sectional].

Exclusion: genetic studies, laboratory studies, modeling studies, virological studies, clinical intervention studies.

Context

Studies will be global in scope and will not be restricted by geographical location

Outcomes

The most important outcomes of this study will be:

• A concept map defining the current utilization of the term “community-based response” in epidemic and pandemic contexts
• A comprehensive list of types of community-based responses to epidemic and pandemic outbreaks
• An analysis of community-based responses that are conducive to epidemic/pandemic prevention and control
• Identification of community-based and external factors that may have positively or negatively impacted prevention, containment, or control on local communities
• Identification of knowledge and practice gaps in the medical, social science, and public health literatures on community-based responses in pandemics

Data Extraction

Titles and abstracts of studies retrieved using the search strategy, as well as those from additional sources, will be screened independently by teams of two reviewers to identify the studies that meet the inclusion criteria. Full texts of potentially eligible studies will then be retrieved and
independently assessed by the two reviewers. Any disagreement between them that arises will be resolved through discussion with a third reviewer.

A standardized, pre-piloted form will be used to extract data from the included studies to assess study quality and findings. Extracted information will include: study setting, disease studied, study population and demographics, details of any intervention if included, study methodology, recruitment and completion rates, and outcomes of interest. Ten reviewers will extract data independently in teams of two. Any discrepancies will be resolved through discussion with a third team member (one of the review authors).

**Quality Assessment**

Studies will qualify for a process of inclusion and exclusion through a process of blind peer review in the methodology described above. Where disagreement occurs within reviewer pairs, a decision regarding inclusion and exclusion for each conflicted article will be submitted to the group of twelve researchers and research assistants for discussion and consideration of bias issues.

**Data Synthesis**

We will provide a narrative synthesis based on coding of the findings from the included studies, structured around type of community-based response, effectiveness of response, study population, and disease studied. Studies will be analyzed using qualitative coding practices linked to a data extraction form that will help to identify common themes. We anticipate utilizing thematic classification techniques based on grounded theory.

There is no anticipated use of meta-analysis currently planned.

**Dissemination Plans**

Several thematically focused papers will be submitted for publication in leading peer-reviewed academic journals. Findings will be circulated through presentations at academic conferences, practitioner meetings, and working groups. Summaries of findings will also be circulated as briefs through Emergency Ebola Anthropology Network.