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DOI: https://doi.org/10.1093/infdis/jiy387

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TITLE: LESSONS FROM THE WEST AFRICA EBOLA EPIDEMIC: A SYSTEMATIC REVIEW OF EPIDEMIOLOGICAL AND SOCIAL AND BEHAVIORAL SCIENCE RESEARCH PRIORITIES

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Conflicts of Interest: The opinions and perspectives expressed are those of the authors only, and do not reflect on the institutions with which they have affiliations. The authors report that they have no conflicts of interest.

In reviewing the literature emanating from the 2014-2016 West Africa Ebola epidemic, we identified thematic differences in the epidemiological and social science approaches that may have impacted the response. We offer recommendations to improve coordinated, multi-disciplinary approaches to health emergencies.

Key words: Epidemics, Pandemics, Health emergencies, Qualitative, Quantitative, Public health, Ebola

Funding Statement: This research was funded by UNICEF New York.

Acknowledgements: Our thanks go to Ben Althouse, Caitlin Rivers, Greig Arendt, and Jeffrey Vadala for their contributions to this work.

Presentation at previous meetings:


ABSTRACT:

This systematic literature review compared the epidemiological (EPI) research and the qualitative social and behavioral science (SBS) research published during the West Africa Ebola virus disease (EVD) epidemic. Beginning with an initial capture of over 2,000 articles, we extracted 236 EPI and 171 SBS studies to examine how disciplinary priorities affected research conducted during the EVD response, with implications for epidemic response effectiveness. Building on this research, we set forth a roadmap for the closer integration of EPI and SBS research in all aspects of epidemic preparedness and response that
incorporates the lessons of the West Africa EVD outbreak. Key priorities include: (1) developing the capacity to systematically quantify qualitative sociocultural variables, (2) establishing interdisciplinary collaborations to improve “risk segmentation” practices, (3) creating and pre-positioning qualitative indicators and composite sociocultural indexes for rapid deployment in outbreaks; (4) integrating novel systems with community resources; (5) developing new techniques for modeling social mobilization and community engagement; (6) prioritizing good data and complex analyses early in emergencies, and (7) learning from past experiences. Our findings support a program of action that situates data collection and analysis in real-time, recursive, integrated efforts to move community attitudes, behaviors, and responses into epidemiological research.

BACKGROUND

The 2014-2016 West Africa Ebola virus disease (EVD) epidemic resulted in 28,616 cases and 11,310 deaths in four countries (Guinea, Liberia, Sierra Leone and Nigeria). New vaccines were developed, and in late 2016 the rVSV-ZEBOV vaccine was found protective against EVD infection.[1] While vaccines may disrupt future EVD outbreaks, the West Africa outbreak was eventually controlled by a combination of classic public health measures, including population surveillance, case identification and management, aggressive contact tracing, isolation, quarantine and mobility restrictions.[2] Social mobilization and local initiatives promoted behavior change among affected populations, also contributing to epidemic containment.[3,4]

The West Africa outbreak prompted one of the largest and fastest mobilizations of epidemiological, clinical, scientific, and social and behavioral science (SBS) research, but also highlighted existing fault lines in knowledge-based response to disease outbreaks. Epidemiological models and forecasts and clinical treatment guidelines were unable to capture the complex socio-cultural conditions and fragile health systems prevailing in these countries. Similarly, social and behavioral
scientists were unable to translate their knowledge of local conditions into epidemiologically-relevant insights. In particular, community-based behavior changes were insufficiently integrated into epidemiological models and forecasts.[5]

We used the West Africa EVD epidemic as an opportunity to assess the extent to which epidemiological (EPI) and SBS research efforts mutually provide the knowledge needed to respond to disease outbreaks. We conducted systematic reviews of the EPI and SBS research and analyzed the themes prioritized in both literatures, to identify how their respective thematic concerns converged or diverged. We use this analysis to highlight the need for more effective research collaboration and response during future infectious disease emergencies. This is central to the International Health Regulations’ prioritization of strengthening national response and capacity during epidemics.

METHODS

We conducted two systematic literature reviews and a subsequent discourse-driven thematic analysis. The main objectives were to analyze the range of thematic topics addressed by the published EPI and SBS literature regarding the West Africa EVD outbreak; to identify thematic areas where the literatures converged or diverged; and to identify opportunities for future multidisciplinary collaboration to support real-time responses, based on knowledge acquired by pre-hoc or concurrent research efforts.

Data sources and search strategy

For both reviews, our methodology was guided by the Cochrane Reviewer’s Handbook,[6] and involved a broad electronic and manual search of the English and French literatures (see supplementary data A).
To obtain data for the EPI and SBS research sets, we conducted a standardized keyword search of most-frequently used research catalogues (Table 1). In both literatures, we prioritized studies with data originating from West Africa during the 2013-2016 epidemic. However, we modified our search strategy early on when we discovered that the ratio of EPI to SBS articles was more than ten to one.

To capture the informal publication patterns of the SBS community, we complemented the primary SBS search with a manual inventory of non-peer-reviewed publications available through topic-specific websites and forthcoming peer-reviewed publications. This strategy was designed to compensate for SBS’s decreased access to data collection opportunities during the epidemic, low levels of research funding, and peripheral role in the research–policy-practice sequence that shaped the epidemic response.

*Table 1: Search strategy*

**Literature screening and catalogue construction**

Study selection used two levels of screening. At level one, abstracts were reviewed for the exclusion criteria (Table 1). Full articles were obtained for all studies accepted at this level. For level two screening, distinct inclusion and exclusion criteria were applied to the two literature sets and were formulated into search sentences (Supplementary Material A). For the EPI literature, studies needed to at least include primary collection or use of field-based data collected from any of the four countries affected. For the SBS literature, selected documents needed to demonstrate original social science analysis, and non-peer reviewed publications required authorship by scholars with current or former institutional affiliations with academic institutions, think tanks, non-profit development or humanitarian organizations.
**Data extraction**

For documents included in the data extraction subset, content was reviewed using a systematic review process conducted independently by two authors (SA and AW). Researchers entered citations and abstracts into the qualitative data analysis software package MAXQDA Analytics Pro v12 (VERBI Software GmbH, Berlin) and cross-referenced abstracts with full-length, searchable files.

Data extraction involved a five-step process.

1. **Independent review of full-text articles using a codebook of themes and sub-themes (developed by SA) based on a pre-screening of the data.** New themes/codes and sub-themes were created as needed using inductive thematic coding.[7,8]

2. **The two reviewers first coded each document separately, and then merged their analyses and reconciled disagreements between the themes and sub-themes ascribed to each to establish a set of interim working themes and sub-themes.** Attributed codes were not mutually exclusive, and documents were coded for multiple variables in the same category when necessary or appropriate. This approach allowed researchers to capture a wide range of themes, but it precluded conventional statistical comparison, single and multiple regression methods, and theme-based weighting.

3. **Text-based searches in data processing software captured matches that were previously missed.**

4. **Researchers reconciled codes and sub-code disagreements to finalize sub-themes.** The themes presented are aggregates of sub-themes presented in Supplementary Material B.

5. **To obtain summary statistics of thematic codes, qualitative codes representing document counts were converted into binary variables which were analyzed for frequencies and percentages in MAXQDA and IBM SPSS Statistics Version 24.0.**
RESULTS

Data retrieval

The initial literature review identified 2170 citations for screening. A preponderance (1572 articles) were rejected according to the exclusion criteria or could not be retrieved. The remaining 598 articles were divided into EPI (n=387) and SBS (n=211) catalogues (Supplementary Material C). A second review to ensure that exclusion criteria had been applied consistently resulted in the final inclusion of 236 EPI articles and 171 SBS articles (Figure 1).

Figure 1: Data retrieval

Study characteristics

EPI and SBS articles differed in content. Among the 236 EPI articles, the four most common types were (1) modeling or forecasting studies, (2) epidemiological status reports, (3) intervention evaluations, or (4) commentaries that introduced novel data. Among the 171 SBS articles, the four most common types were (1) original qualitative research, (2) commentaries/discussion pieces, (3) ethnographic narratives, and (4) guidance documents.

All studies were analyzed for research location and study period. Although the research often overlapped the epidemic “phases”, most EPI research and SBS writing was conducted during phase 1, the period of peak mortality in Sierra Leone and Liberia (Table 2). However, due to inconsistent reporting, it was difficult to precisely associate data sources with particular countries; due to imprecision in early EVD reports, many publications included data that were unclearly disaggregated by country.[9,10]

Table 2: Sample size, location (mentioned as a focus or source of data) and timeframe of study
Comparison of thematic areas identified by literature type

The analysis identified a total of 29 composite thematic areas (Table 3); these are aggregates of the 327 sub-themes listed in Supplement A. Table 3 presents the number and percentage of articles within each data set that addressed the theme or sub-theme within each set. These findings are presented side-by-side, to illustrate how frequently each literature addressed key themes relevant to epidemic response. We interpret frequency to indicate disciplinary priorities during the epidemic, as well as researchers’ access to original and historical data.

Table 3: Themes and ratios of themes in EVD publications by research type with shading to indicate greater proportion

EPI articles prioritized more research on clinical and patient care (59%); diagnosis of EVD (42%), including sensitivity and specificity (46%); transmission (75%), incidence, mortality, and characterizing local outbreaks (84%); modeling and forecasting EVD trends (50%), outbreak investigation (63%); and Ebola virology (23%). SBS articles also prioritized transmission (47%), but included other themes related to prevention and EVD response. These included: health communications (44%), social mobilization and community engagement (63%); alternative healthcare-seeking practices and traditional and informal healthcare providers (63%); economic issues; traditional and local beliefs; political issues (78%); funerary practices and burials (59%); population mobility (66%); healthcare workers (57%); psychosocial experiences around risk, mortality, and stigma (88%); and the challenges confronting EVD survivors (30%). They also included qualitative documentation on the risk factors affecting vulnerable populations (older persons, children, the disabled, pregnant women, and orphans [33%]). In each of these examples, the respective literature leaned, usually substantively, towards the themes listed.

While epidemiology traditionally focuses on associations and outcomes, during the West Africa EVD epidemic the EPI literature often addressed access to beds, presence or absence of contact tracing
measures, health worker utilization of protective gear and infection prevention and control practices. SBS studies were flagging factors like gender, social roles, vulnerabilities, access to healthcare, food insecurity, and mobility in July-September 2014, but these factors were not integrated into epidemiological analysis until later in the outbreak (approximately November-December 2014). This gap is likely due to epidemiologists’ poor access to such data, limited by on-the-ground data collection capabilities, and methodological differences in defining SBS variables for quantitative analysis. Whether due to a lack of access or resources, or low priority, SBS studies less frequently engaged with transmission (47% versus 75% for the EPI literature), clinical care (46% v 59%), and epidemiological concerns (13% v 84%) at scale, and did not assess incidence, reproduction rates or transmission chains, to inform response strategy and policy.

The EPI and SBS literatures converged in commonly addressing themes related to public health response (76% and 85% respectively), health systems (74% and 75%), population mobility (53% and 66%) and risk factors (43% and 41%); there were also other less common themes of similar frequency across the two literature sets. However, the two catalogues dealt with some themes, like national capacity and health systems, in different ways. For example, on health systems, EPI studies focused on capacity gaps and needs for support,[11–13] while SBS studies focused on labor recruitment/retention and community confidence in government-run health services, including local perceptions of their morality and ethics before and during the epidemic.[14–16] SBS analyses also attempted to directly integrate historical underdevelopment, systemic injustices, patterns of structural and political violence and governmental malfeasance into their analyses.[17–19] Risk factors, like sex, also involved thematic splits. SBS literatures pointed to gender-specific transmission pathways,[4,20] while EPI studies emphasized gender similarities in infection and mortality rates.[21,22]

Both literatures dealt seriously with public health sub-themes, but paid attention to very different issues related to the response. EPI studies tended to focus on its effectiveness, reach, and impact,[23–25] while SBS studies focused on inequality in public health capabilities,[26] the legacy of vertical health
programs,[27] and the EVD response’s failure to understand existing structural gaps and public health capabilities.[28–30]

Where the SBS and EPI literatures diverged, they diverged widely. While each frequently acknowledged similar core themes, they rarely integrated these concerns into their research designs or analysis. For example, EPI articles described cultural and behavioral influences informing funerary practices and community resistance, but struggled to integrate them into models.[31,32] Similarly, SBS literature often acknowledged clinical and epidemiological concerns like standards of care, sources of risk or transmission dynamics, but did not transform sociocultural factors into quantifiable observations, events or methods at the scale needed to inform the response. Furthermore, while the SBS literature often acknowledged clinical and epidemiological concerns like transmission pathways/dynamics, case time-to-reporting and treatment standards, it did not apply such insights during social-science-guided interventions. In several areas of common concern (misinformation about the epidemic, funerary practices and community engagement) quantitative approaches had difficulty integrating the qualitative depth of the SBS literature with the response needs.

These divergences resulted in differing empirically-relevant conclusions. For example, EPI studies hypothesized that the disruption of health services may have impacted non-Ebola mortality; while the SBS literature contended that EPI studies may have failed to account for widespread, continued services by private, informal or traditional healthcare providers.

**DISCUSSION**

To ensure the rapid, effective, targeted, and locally sensitive allocation of epidemic containment measures along the prevention-response continuum, future epidemic events require better pre-positioning,
collaboration, and real-time integration of epidemiological and social science capabilities. Some EPI research does not require a behavioral component; similarly, not all health-focused SBS research must be contextualized in local epidemiology. However, our review of the EPI and SBS literature on the West Africa EVD epidemic demonstrated that these two disciplines dealt with some core themes in very different ways, reducing their capacity to mutually augment the response. Post-EVD reviews have acknowledged that there is need to harmonize SBS and EPI research to inform global epidemic and pandemic preparedness and response capacities.[33,34] Efforts are underway, but SBS research remains associated with health communications (e.g. WHO’s Social Science Unit sits within the Health Communications Capacity Unit), and is not integrated in preparedness and response coordination during global health emergencies. Indeed, the approaches used by the two literatures often seemed diametrically opposed. While the EPI literature drew upon broad population data (e.g. density, age, sex, language group, socio-economic situation) to make general inferences without incorporating local insights (e.g. cultural practices, traditional structures, mobile phone penetration, population movements etc.). By contrast, the SBS literature used small samples to make sweeping inferences for which there was scant epidemiological data. For example, anthropological studies that used individual-level data (rather than historical analysis or literature reviews) included samples that ranged from less than ten key informants to >800 households; while studies presenting community-level data tended to include a small sample of communities (n=1-5). Such trends suggest the need for real-time research that includes larger SBS sample populations, more detailed and inclusive epidemiological data collection, including on SBS themes, and improved collaboration between both approaches.

Are the two literatures irreconcilable, or are other methodological issues at work? The EPI literature’s different priorities suggest the difficulty of quantifying and incorporating sociocultural, historical, political and economic constructs in ways directly applicable to the epidemic context. At the same time, while SBS literature often acknowledged clinical and epidemiological concerns, it did not
transform sociocultural factors into quantifiable observations or methods at the scale needed to inform the response.

While recognizing that such approaches cannot be applied in all health emergencies, this study suggests that such disciplinary segregation creates missed opportunities in global health emergency and humanitarian response. Box 1 summarizes our recommendations to address this challenge; they are applicable to international as well as national response efforts.

**Box 1: Recommendations to build capacity for future EPI/SBS work in epidemic contexts**

Novel strategies are required to systematically quantify sociocultural factors for epidemiological purposes. To make SBS insights meaningful and actionable, researchers should document relevant sociocultural factors (risks [behaviors, beliefs, practices] that characterize certain communities [defined geographically or by other criteria]) to enable their (ideally quantitative) integration into epidemiological models. We found that during the West Africa EVD epidemic, data collection prioritized quantitative benchmarks like time-to-reporting, time-to-clinic, or contact-tracing estimates, but ignored important SBS influences on these variables (for example, informal social learning pathways; informal healthcare providers engaged in community education or infection prevention; community-driven initiatives; cooperation between local governments, healthcare workers and community leaders). Such influences undergirded recent responses to influenza in China[35] which learned from SARS of the need for community-wide approaches.

Lessons from other fields can guide this effort. In the financial sector, detailed historical knowledge of sub-population groups has been successfully applied in risk modeling to allow corporations to sub-divide or segment risk in more refined ways. Collaborations between the social sciences and epidemiology can quantitatively define population “risk segments” (economic groups; communities) that predict exposures, informing response design and implementation. This approach pools individuals into homogeneous segments defined by historical tendency to perform similarly, either incidentally or
longitudinally. While initiated in HIV research,[37] and applied to reduce harmful practices responsible for newborn tetanus [38] and kuru [39], this approach has been little tested in global health or emergency response research. Often the risk has already been identified by research into associations with disease incidence. Collaborations are needed to underwrite more creative, historically and locally-aligned characterizations of risk (modeled or observed) to support contextualized preparedness or response.

Lessons can also be taken from validated mental health approaches to quantifying qualitative diagnostic observations. Sophisticated strategies support the transformation of patient interviews into valid diagnostic scores,[40,41] including extensive controls for subjective, linguistic and cultural elements, as needed in epidemic preparedness or response. In a similar manner, epidemiologists and social scientists can collaboratively establish qualitative or semi-quantitative indicators of epidemic progression or risk; community support, resistance or engagement; social mobilization, and intervention effectiveness. This knowledge can be rapidly utilized to develop responses using EPI approaches targeting disease spread but founded upon SBS principles.

Sierra Leone anthropologist Paul Richards wrote: “It is striking how rapidly communities learned to think like epidemiologists, and epidemiologists to think like communities”.[42] Reductions in poliovirus transmission have been partly accredited to explicit community engagement and ownership, linked to sanitation and hygiene and vaccination uptake.[43] SBS and epidemiological researchers can collaborate to situate communities at the center of real-time, rolling data collection to reflect disease transmission and response effectiveness. Rapid data collection systems can be pre-positioned and integrated with psychosocial, knowledge-attitudes-and-practice and intervention impact measures, and with measures of community engagement and social mobilization.

These systems can enable international actors, states and other stakeholders to receive real-time information and respond appropriately. Aggregate, or composite qualitative indices of risk, social mobilization, community engagement, and response effectiveness can be pre-conceived and validated for
use in status updates. These methodologies are well established during successful vaccination campaigns, which are known for their military precision and local support.[44] This approach encourages use of untapped community resources and the integration of sociocultural factors into epidemiological models.

There are consequences for failing to advance this agenda. The non-alignment of EPI and SBS research during the West Africa Ebola epidemic means that questions about what transpired, what worked and didn’t work, who was responsible and affected and how or whether the epidemic curve was moved by the local and international response, will likely remain unanswered. Conventional wisdom holds that during the outbreak, aggressive campaigns of isolation, contact tracing, safe burial and social mobilization reduced disease transmission. But in our assessment, the research evidence on the relationship between Ebola transmission, interventions and behavior change is scant, indicating poor understanding of the relationship between sociocultural factors and EVD transmission, and the impact of interventions on overall epidemic trajectories.[45,46]

Data quality and analysis is another vital issue in this regard. Although genomic sequencing and clinical characterizations were conducted early and proved robust, reviewers of the global response found that early case-reporting data in West Africa was weak;[33] accordingly, evidence for the sociodemographic, geospatial and cultural correlates of transmission and prevention were lacking. Where qualitative data was integrated into the response, concepts like “community resistance” were insufficiently defined for inclusion in reports. More medical anthropology is needed to characterize and quantify risks, particularly those with potential for widespread population health impact.

Moreover, data collection is usually undertaken to keep authorities informed, but must also be integrated into well-supported analytical and modeling capabilities within and beyond response structures.[47–51] In both the West Africa EVD and global Zika outbreaks, mobile technologies and grassroots surveillance became increasingly important for collecting large quantities of (often
unanalyzed) data. Data access restrictions that inhibited inter-disciplinary coordination were problematic in West Africa; these must be lifted.[48]

There are limitations to our study. First, it was impossible to rely on primary data, so research in both disciplines depended also on secondary data sources, ranging from external datasets to informal qualitative reports. Many epidemiological models utilized the same incomplete datasets (viral hemorrhagic fever databases, WHO Situation Reports, secondary district and county-level data), and social science reports utilized small numbers of respondents or secondary reports. Thematic homogeneity may be due to limited data access specific to this epidemic. Second, due to the international sharing of several datasets on the epidemic, it was not possible to control for kin relationships, with multiple publications describing the same or overlapping sets of patients. Thus, a meta-analysis of this data is likely not possible. Several important studies included in both libraries included numerous kin publications. Third, themes were established using a grounded theory approach, subjected to a peer review process. However, restricted funding made it impossible to undertake comprehensive, teams-based peer-review, resulting in some overlap between themes and sub-themes. Finally, to ensure that publication bias did not unduly restrict our review of the SBS literature, we included some SBS studies based on limited data, historical analysis and non-peer-reviewed articles.

How did socio-political, economic, migration, and sociocultural trends impact EVD transmission? How could a more sophisticated understanding of health systems capacity, behavior change, human mobility, mass communications, political contexts, and social vulnerability have impacted the speed and roll-out of epidemic response implementation? Regrettably, for an event that put three countries in states of emergency for nearly two years and killed more than 11,000 people, we will never have answers to these questions that we didn’t know we had, due to failure to design data collection, modeling, mixed EPI and SBS research and analysis accordingly. Integration of SBS and epidemiological approaches is needed for ensuring future epidemic response and building this capacity into health systems. Agile, linked qualitative and quantitative data collection and analysis efforts must be developed
and used to drive surveillance, forecasting, policy, and resource prioritization. There are no informal networks, shortcuts or workarounds that can substitute for overcoming capacity gaps that are currently causing the “missed connections” and “blind sides” between the SBS and epidemiological domains.

References


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27. Wesley PJ. Liberia’s Ebola Epidemic: Did the Government Fall Asleep at the Wheel. Cult


44. John TJ, Vashishtha VM. Eradicating poliomyelitis: India’s journey from hyperendemic to polio-


Table 1: Search strategy

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Primary data sources outside of Liberia, Guinea, Sierra Leone, Nigeria

*The Health Communications Capacity Collaborative, the Ebola Response Anthropology Platform, and the Réseau Ouest Africain SHS Ebola

**see SUPPLEMENTARY MATERIAL A for complete search string
Table 2: Sample size, location (mentioned as a focus or source of data) and timeframe of study

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* Any study that included a country other than Liberia, Guinea, Nigeria, or Sierra Leone as part of its reference group in addition to the core 4 countries (e.g. Democratic Republic of the Congo, Uganda)

** Phases are based on the United Nations Mission for Emergency Ebola Response, to provide uniformity across countries
Table 3: Themes and ratios of themes in EVD publications by research type with shading to indicate greater proportion

<table>
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Box 1: Recommendations to build capacity for future EPI/SBS work in epidemic contexts

1. Develop a program for the systematic quantification of locally-appropriate sociocultural factors for epidemiological purposes;
2. Establish interdisciplinary collaborations to refine “risk segmentation” methodologies and practices for better real-world accuracy;
3. Create and pre-position qualitative indicators and composite social indexes that can be rapidly deployed during epidemic outbreaks;
4. Use untapped community resources to create real-time, rolling data collection and response integration capabilities;
5. Develop new techniques for modeling social mobilization and community engagement;
6. Prioritize accurate, high-quality data collection and rapid development of multiple modeling frameworks early in the emergency response;
2170 articles retrieved

1572 meet exclusion criteria or are unable to be retrieved

598 studies retrieved (211 SBS, 387 EPI)

151 EPI studies meet exclusion criteria

40 SBS studies meet exclusion criteria

407 studies retrieved (171 SBS, 236 EPI)

236 EPI studies included

171 SBS studies included
1. Develop a program for the systematic quantification of locally-appropriate sociocultural factors for epidemiological purposes;
2. Establish interdisciplinary collaborations to refine “risk segmentation” methodologies and practices for better real-world accuracy;
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