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Lessons Learned from the September 11th Disaster: A State Health Agency Perspective

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Abstract: The New York State Department of Health has conducted a number of studies over the past 10 years investigating health impacts related to the September 11, 2001 (9/11) disaster among New York City residents and New York State World Trade Center (WTC) responders. Efforts to evaluate the health effects of WTC exposures in these cohorts presented numerous challenges, including study design and associated concerns about bias, identifying the affected populations, gaining community support and participation, and determining the most appropriate clinical testing and follow-up approaches. The unique position of a state public health agency provided multiple points of support for these efforts. An overview of what was found and the lessons learned during the response to the 9/11 disaster is presented, from the viewpoint of a state public health agency.

Keywords: 9/11, WTC, World Trade Center, first responders, disaster epidemiology

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Introduction

Ten years ago, we began the first investigations of health impacts related to the September 11, 2001 (9/11) disaster among New York City (NYC) residents and New York State (NYS) World Trade Center (WTC) responders. After a substantial effort assessing and following-up their health, we summarize and share what we found and the lessons learned from the 9/11 disaster, from the viewpoint of a state public health agency.

Health Impacts of the WTC Disaster Among NYC Residents and Rescue Workers

In 2002, the NYS Department of Health (NYSDOH) conducted a retrospective cohort study to assess the respiratory health impacts of 9/11 among NYC residents. Results showed that affected-area residents experienced more lower respiratory symptoms (LRS, 55.8%) and upper respiratory symptoms (URS, 122%) three months post-9/11 compared to control area residents (20.1%).^{1,2} Both URS and LRS were three times more persistent one year after 9/11 in the affected areas compared to control areas. Follow-up approximately 2–4 years post-9/11, showed declines in LRS but higher proportions of persistent symptoms among affected area residents.³ In a NYSDOH study of NYS WTC responders, URS and LRS were reported by nearly half of participants. One third reported a psychological symptom. Respiratory and PTSD symptoms were associated with being in the dust cloud on 9/11.⁴ Follow-up studies found WTC exposure was associated with LRS but not with reported asthma two years post-9/11. Smoke exposure may have had a greater lower respiratory impact than resuspended dust.⁵ Chronic bronchitis was identified as a persistent problem 5-years post-9/11. Participants with the highest exposures were more likely to experience increased severity of asthma and/or LRS.⁶ Additional follow-up, 6 years post-9/11, found using a respirator with canister was protective for central airways in responders exposed to dust and smoke.⁷ Testing of biological samples showed WTC responders were exposed to perfluorochemicals and polychlorinated dibenzofurans.^{8,9} Comparing residential with occupational exposures, we found new-onset LRS post-9/11 was slightly higher in NYS WTC responders than residents of

affected areas.^{1,2,5} Cough was the predominant LRS among both populations.^{2,5}

Methodological Challenges and Strategies to Address Them

We experienced many challenges and developed corresponding strategies in conducting these epidemiologic studies after the WTC disaster. The first problem we encountered was recruitment difficulty because a significant number of residents moved out of the affected area after 9/11 and centralized rosters were not available to track WTC responders. Some individuals refused to answer questions related to the disaster that provoked an emotional reaction, or were overwhelmed with requests for participation from multiple agencies.

Voluntary response could introduce selection bias, i.e., people who experienced symptoms and lived or worked in the affected areas were more likely to participate than those who did not. This bias may have affected the representativeness of our studies and could also have led to overestimation of disease incidence in exposed residents and responders. We minimized this bias by: (1) emphasizing the importance of participation regardless of respiratory issues and using general terms such as “breathing problem”; (2) employing similar recruitment efforts in residential areas or among all WTC responders to reduce differential motivation; (3) using exclusion criteria to limit misclassification due to mobility and occupational exposure; (4) obtaining similar response rates and comparable demographics between exposed and control populations; and (5) estimating the change in exposure-disease association for areas targeted and non-targeted for additional recruitment.

Another important challenge is recall or reporting bias, i.e., affected-area participants or exposed responders might have recalled and reported more symptoms than the controls. To minimize this bias, we asked for specific time frames, severity, and frequency of symptoms, and lists of prescription medications. We also assessed memorable events such as new diagnoses, emergency department visits, and hospitalizations, as they are less prone to recall bias. To estimate reporting bias, we also queried conditions unrelated to WTC and excluded individuals who responded affirmatively to all health conditions. Finally, in some sub-groups, we conducted pulmonary



function tests, methacholine challenge tests, and used fractional exhaled nitric oxide (FE_{NO}) as a biomarker to validate self-reported symptoms.

Another challenge we faced was a lack of objective exposure measurements. A semi-quantitative exposure assessment was conducted which categorized participants by different patterns of exposure. The algorithm incorporated dust and smoke exposure, time period, and duration on-site, location of work, personal protective equipment used, and quantitative data from air monitoring in pertinent locations.¹⁰

Additional Lessons Learned and Strategies for Future Disaster Responses

1. *Partnership with local community groups and other organizations is a critical element for success in a large community study after a disaster.* Collaborators from New York University, several NYC medical service groups, and community organizations offered valuable assistance with recruitment, grassroots outreach, and follow-up in our residential study. For instance, we held meetings with local stakeholders before and after recruitment to identify community needs, identify the best approaches for recruiting local populations, and to receive feedback on our study procedures. Collaborators worked with landlords in NYC apartment buildings to facilitate recruitment efforts. Without the valuable knowledge and assistance of individuals familiar with the areas and populations living near the disaster site, our efforts would likely have been less well-organized. Existing partnerships between NYSDOH and NYC-based public health groups also facilitated our study procedures by generating immediate points of contact and a familiarity with the affected area.
2. *Clinical field tests are a useful method to track health impacts in the immediate aftermath of a disaster.* One challenge for an epidemiological response to a disaster is collecting pertinent health data in a suitable time frame. NYSDOH studies using impulse oscillometry and offline FE_{NO} allowed us to gain experience in the use of these methods in the field.⁴ Our experience indicates these tests can assist in assessment of respiratory effects of disaster-related exposures and can be successfully utilized in the field, following strict

protocols. We employed these tests several years post-9/11, but ideally they would be performed shortly after a disaster and at periodic intervals thereafter. This would allow researchers to better track health impacts post-disaster and allow health care professionals to administer appropriate treatments in a timely manner.

3. *The efficiency of IRB review procedures must be improved.* Most similar disaster research would require full Institutional Review Board (IRB) consideration, which can be time-consuming and limiting when expediency is desirable. While IRB review is critical in assuring human subjects' protection and research integrity, the review process did result in significant delays for many WTC-related projects, which may have impacted participation rates and subject recall. In addition, we now know that some of the most profound health impacts resulted from exposures in the days and weeks immediately after 9/11, before most research studies were approved. A fast-track IRB approval process and specially-scheduled IRB meetings were facilitated by the NYSDOH to improve review efficiency, given the urgency of the events of 9/11. However, the ability to react more efficiently to such an unexpected event would have been ideal. Future studies of disasters may benefit from a review process specifically designed to deal with the need for an immediate research response while enabling multi-agency collaborations and maintaining research integrity.¹¹ Having such a mechanism in place before a disaster occurs could allow a more timely response than was possible in the weeks after 9/11.
4. *The unique strengths of a state public health agency should be utilized.*
 - a. *Multidisciplinary research teams:* In our WTC studies, we leveraged NYSDOH's unique resources and networking capacity to assemble teams with expertise in clinical medicine, epidemiology, biostatistics, toxicology, laboratory science, and community outreach. The multidisciplinary training of the team was complementary and critical to the success of this project. We worked closely with local universities and other government agencies, both state and federal, to expand the available expertise to the betterment of the research. Access to such



resources allows for an efficient and effective research response to disasters.

- b. *Disaster preparedness programs*: NYS has developed programs that provide education and training for disaster preparedness and management at all levels, including for first responders, hospitals, local government agencies, and the public. Vulnerable populations have been identified. Available resources include outreach materials, toolkits, checklists, course suggestions, and web sites. NYS also conducts preparedness exercises periodically. These existing efforts and available infrastructure provide for a rapid public health response.
- c. *Databases and technology infrastructure*: The database of NYS WTC responders is updated periodically and will be maintained to allow for future studies as appropriate. In addition, previously collected biological samples have been archived and analyses may be expanded in the future. Based on our WTC experiences, templates for questionnaires and related documents have been developed to allow a more efficient epidemiological response to future disasters. While every disaster event will be unique, having templates and guidance documents prepared in advance will allow future studies to be designed and implemented more quickly and effectively, based on the experience we have gained post-9/11. A leading program for the surveillance of environmental hazards and health effects in New York is our Environmental Public Health Tracking Program (EPHT). It is part of a network of 17 states and NYC developed by the US Centers for Disease Control and Prevention to enhance understanding of hazards in the environment, exposures to these hazards, and their relation to disease change over time or across regions. Diseases currently tracked include asthma, birth defects, other birth outcomes such as low birth weight, cancer, heart disease, stroke, and vital statistics. Other existing NYSDOH databases include the Health Emergency Response Data System, Hospital Available Beds for Emergencies and Disasters, Syndromic Surveillance

System, Health Emergency Response Data System, and the Biomonitoring Surveillance Program. These available datasets have varying timeliness, provide baseline and emergency information, and include both environmental and health data. The EPHT and other databases maintained by NYSDOH can be used to identify excess morbidity or mortality related to environmental disasters, where critical baseline information is often lacking.

Conclusions

The WTC disaster had long-term health impacts for NYC residents and NYS WTC responders. As a state environmental health agency, we had an important role in responding to this tragedy. We developed useful methodologies while evaluating the impacts of this event, learned valuable lessons which may be applied in future natural and manmade disasters, and identified surveillance and research priorities for emergency response.

Author Contributions

Conceived and designed the experiments: SL, MPM, EFF, SAH. Analysed the data: RJ, MLH. Wrote the first draft of the manuscript: SL, MPM. Agree with the manuscript results and conclusions: SL, MPM, RJ, MLH, SAH, EFF. Jointly developed the structure and arguments for the paper: SL, MPM, RJ, MLH, SAH, EFF. Made critical revisions and approved final version: SL, MPM, RJ, MLH, SAH, EFF. All authors reviewed and approved of the final manuscript.

Disclosures and Ethics

As a requirement of publication author(s) have provided to the publisher signed confirmation of compliance with legal and ethical obligations including but not limited to the following: authorship and contributorship, conflicts of interest, privacy and confidentiality and (where applicable) protection of human and animal research subjects. The authors have read and confirmed their agreement with the ICMJE authorship and conflict of interest criteria. The authors have also confirmed that this article is unique and not under consideration or published in any other publication, and that they have permission from rights holders to reproduce any copyrighted material. Any disclosures



are made in this section. The external blind peer reviewers report no conflicts of interest.

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