



## Policy Mini-Symposium

## The role of epidemiology in disaster response policy development



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## ABSTRACT

**Purpose:** Disasters expose the general population and responders to a range of potential contaminants and stressors which may harm physical and mental health. This article addresses the role of epidemiology in informing policies after a disaster to mitigate ongoing exposures, provide care and compensation, and improve preparedness for future disasters.

**Methods:** The World Trade Center disaster response is used as a case study. We examine how epidemiologic evidence was used to shape postdisaster policy and identify important gaps in early research.

**Results:** In the wake of World Trade Center attacks, epidemiologic research played a key role in identifying and characterizing affected populations, assessing environmental exposures, quantifying physical and mental health impacts, and producing evidence to ascribe causation. However, most studies suffered from methodological challenges, including delays, selection biases, poor exposure measurement, and nonstandardized outcomes. Gaps included measuring unmet health needs and financing coverage, as well as coordination across longitudinal cohorts of studies for rare conditions with long latency, such as cancer.

**Conclusions:** Epidemiologists can increase their impact on evidence-based policymaking by ensuring core mechanisms are in place before a disaster to mount monitoring of responders and other affected populations, improve early exposure assessment efforts, identify critical gaps in scientific knowledge, and coordinate communication of scientific findings to policymakers and the public.

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## Introduction

After most disasters, whether natural or man-made, policies are needed to address physical and mental health consequences and mitigate health impacts of future disasters. Forces shaping responses to disasters include politics, economic realities, societal values, and the nature of the disaster itself. Ideally, response and policymaking is also guided by scientific evidence, much of which is derived from the field of epidemiology. Epidemiologic studies can play a critical role in estimating the size and geographic

dimensions of affected populations, quantifying short- and long-term health outcomes, and providing evidence to ascertain causal links between exposures and health outcomes, particularly with respect to long-term conditions. Epidemiologic research can also guide policy formation for protection of first responders, cleaning of affected areas, and defining criteria for disability compensation.

Unfortunately, scientific evidence on health impacts tends to accumulate slowly postcrisis and is rarely generated from randomized clinical trials. Furthermore, regardless of methodology, the quality of initial evidence is frequently imperfect and conflicting across studies. In contrast, the process and timeline for policy formation in response to a disaster often involves rapid decision making to address immediate and long-term needs. Because policy decisions can have a major impact on pace of recovery and service delivery, a major challenge is how to improve

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the generation of high-quality evidence on the burden and causes of health outcomes in a timely fashion and to keep policymakers abreast of what is known and not known over time. Epidemiologic science offers important examples of promises and pitfalls of scientific research. This article uses a case study approach to examine health impacts from the terrorist attacks on the World Trade Center (WTC) towers on September 11, 2001, specifically focusing on the need for and influence of epidemiologic studies on policy formation during the decade after the attacks.

#### *Case study: the WTC attack*

The attacks on the WTC towers on September 11, 2001 in New York City (NYC) yielded the largest loss of life resulting from a terrorist act in US history, killing 2751 people and acutely exposing hundreds of thousands to mental trauma associated with these horrific events and to potentially harmful environmental exposures [1–3]. In brief, two hijacked passenger airplanes were crashed into the North and South towers of the WTC complex, causing them to collapse and destroy other buildings in the WTC complex. Building and office material were pulverized and dispersed in a large cloud or plume that was breathed by individuals in the vicinity. Many of these same people personally witnessed horrific events, such as individuals jumping or falling from buildings or the plane crashing into the buildings themselves. Homes and workplaces were destroyed, damaged or covered in dust, which resulted in prolonged displacement for many residents. In the aftermath, efforts were mounted to rescue survivors from the WTC “pile,” dismantle the destroyed towers and rebuild the community, which exposed responders and maintenance crews to environmental contaminants and a range of other workplace hardships including psychologically stressful events.

#### *Need for epidemiologic research to guide policy formation*

The scale of the attacks on September 11 was immediately recognized to be unprecedented for the nation. Widespread psychological trauma was immediately expected, but recognition and knowledge regarding possible health ramifications of such an acute environmental disaster was slow to form in the days immediately after the event. This case study focuses on five main areas where epidemiologic science was used or needed to guide policy: (1) responder protection and exposure assessment, (2) acute physical health effects research, (3) mental health effects research (4) long-term health effects research, and (5) measuring unmet health care needs, disability, and compensation.

#### **Responder protection and exposure assessment**

The aftermath of the WTC disaster involved an immediate response by a wide variety of responders, ranging from firefighters and police to unaffiliated citizen volunteers who arrived to render assistance. In the weeks and months that followed, a large number of additional responders joined relief efforts in and around the WTC site, including National Guard personnel, government employees, ironworkers, and other site remediation workers. During the initial efforts, no single entity assumed overarching responsibility for compiling a list of responders, for protecting responders’ health, or for providing appropriate personal protective equipment (PPE), resulting in delayed recognition of possible health concerns and delayed availability of such equipment. Three primary challenges in protecting responders were (1) determining precisely who responded, (2) ensuring whether responders had adequate protective equipment and training and/or guidance on proper use, and

(3) identifying which, if any, harmful environmental contaminants responders were being exposed to.

Epidemiologic research ultimately played a key role in addressing all three of these challenges, including assembling cohorts of responders to monitor subsequent health consequences, describing responder respirator use, and linking results from environmental health modeling to reported work shift information to improve assessment of exposure to environmental toxins. As with PPE availability, the importance of mounting systematic surveillance for possible health concerns among the first responders was delayed by the lack of defined leadership. For example, information on who was on site and for how long was not collected in the initial phases of the response [4]. This not only presented an immediate obstacle to ensuring that responders received and properly used PPE but also it also affected the quality of subsequent epidemiologic findings. When responders were finally enrolled in epidemiologic cohorts, the lack of lists precluded active recruitment of most responder groups, leaving only the option of voluntary enrollment. As a result, selection biases affected the validity of findings. Earlier rostering of responders would have improved accountability for responder protection and allowed appropriate follow-up for health tracking purposes.

Regarding PPE use, epidemiologic findings from retrospective surveys conducted among cohorts of WTC responders suggest that availability and use of appropriate PPE, particularly during the immediate response, was poor. According to one large study of WTC rescue–recovery workers, half wore no respiratory protection during the first day of response and another one-third wore un-rated disposable masks only [5]. A study of the Fire Department of New York (FDNY) indicated that 45% of those present at the time of the actual WTC collapse reported not wearing a respirator, and 35% who arrived later that day wore no respirator [6]. A targeted study of New York State personnel found that almost two-thirds reported ultimately using some type of respiratory protection, but the most common types used were one-strap and two-strap dust masks [7]. According to an investigative report from the RAND Corporation, most law-enforcement agencies did not allocate enough funding to stockpile respiratory protective equipment for disaster response [8]. In terms of training, fit testing, and ongoing use, approximately one-third of workers in a large cohort of WTC responders reported having no PPE training at all during WTC-related work, less than half wearing masks reported having been properly fit-tested, only one-third reported cleaning the respirator before use, and approximately 20% replaced cartridges regularly [5]. Later epidemiologic findings showed that responders with any respiratory protection training had a greater likelihood of appropriate use of respiratory protection during response activities [7] and that proper respirator use was linked with a protective effect for some respiratory health impacts, including development of asthma [9,10].

The documented poor availability of proper PPE and limited training and/or fit testing for many responders in the early response efforts emphasizes the policy importance of clearly delineating responsibility for the first responder and recovery worker health and safety, and prevent preparation and allocation of adequate resources for responder protective equipment among the first-response agencies.

In terms of exposure assessment, documenting the environmental contaminants that responders and community residents were actually exposed to posed a particularly difficult challenge. Although the WTC attacks occurred in a large urban area with significant air quality monitoring capacity, no direct measurement of airborne contaminants occurred near the towers until 3 days after the collapse, in part because of the citywide focus on acute lifesaving efforts but also perhaps reflecting the broader widespread delayed recognition of potential physical health risks. The

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