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## Original article

## 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

exact composition and breadth of the initial plumes from the collapse of the twin towers therefore remains unknown, leaving epidemiologists with weaker sources of information on physical exposure measurements.

To guide exposure assessment, geostatistical models of exposure were developed taking into account time, space, local wind, and atmospheric conditions [2,11]. Generally, studies confirm that dust particulate levels decreased sharply with distance from the WTC site, and large reductions in exposures were also observed over time due to remediation and rain events [11,12]. Samples of settled dust were found to consist predominantly of coarse particles (95%) and contained pulverized cement, glass fibers, asbestos, lead, polycyclic aromatic hydrocarbons, polychlorinated biphenyls, and polychlorinated furans and dioxins. Dust pH was highly alkaline (pH 9.0–11.0), a characteristic later hypothesized to be a contributor to observed cases of bronchial hyperreactivity [1,2].

Once environmental sampling began, another major post-disaster challenge was to determine which contaminants should be measured and which had the greatest human health risks. The science to inform this decision was, at best, incomplete. Individual contaminants measured several days after the attacks included asbestos (September 14); benzene, polychlorinated biphenyl's, dioxins, and lead (September 16); fine particulates smaller than 2.5 microns (September 21); and polycyclic aromatic hydrocarbons (September 23) [12]. One study identified that ambient air levels of dioxin for lower Manhattan residents were six times higher than predisaster air concentrations, and that workers in the restricted area around the pile were likely to have encountered levels of dioxins and furans 100 to 1500 times ambient levels before the attacks [12]. Yet, exposure to WTC dust and not necessarily dioxin has since been more consistently linked to poor health outcomes [13]. Mathematical models suggest that because 95% of human exposure to dioxin and furans tends to occur through food consumption and only 1% by inhalation, WTC pile workers exposed to high levels of dioxin for 3 months had only an estimated 17% higher burden of these two toxins after 3 months of exposure, and modeled body burden would have returned to near background levels after leaving the area or after ambient levels dropped to background concentrations (by December 2001 in the areas near the WTC site and by May 2002 at the site) [12]. Findings from these models suggest that exposures to dioxins and furans did not significantly increase lifetime cancer risk [12,14].

### Acute physical health effects research

In the days immediately after the attacks, surveillance efforts on the human health impacts were initially focused on quantifying injuries and deaths [15–19] and monitoring for possible bioterrorist attacks [20,21]. However, the initial high mortality among rescue and recovery workers [22] coupled with difficult environmental conditions, long shifts, and high emotional intensity [23,24], drew international attention and funding to the issue of rescue–recovery worker health within the first 1 to 2 months. Attention on health impacts to other affected populations, such as local residents and business employees and passersby were slower to garner attention [25]. Epidemiologic studies have since played a key role in linking dust exposure from the collapse of the WTC towers to subsequent respiratory health outcomes, and a growing body of evidence has been accumulating on linkages to other health outcomes as well.

The majority of early epidemiologic studies were performed by teams of researchers affiliated with one of four dedicated programs, three of which provided specialized testing and treatment that ultimately became known as “Centers of Excellence” on 9/11-related health issues [26]. Two of them were early medical

monitoring programs that established epidemiologic cohorts of rescue and recovery workers soon after the attacks—one at FDNY and the other at Mount Sinai Medical Center. A third cohort, the WTC Health Registry, was established in 2003–2004 as a prospective exposure registry that enrolled volunteers from all directly affected populations, including residents and other non-rescue–recovery workers. The fourth program was later established at Bellevue Hospital Center to assess and treat WTC-related conditions for residents, students, WTC-related response workers or passersby affected by 9/11.

Each of the programs experienced delays in receiving funding and approvals from their institutional review board (IRB) offices [27], resulting in delays in launching studies until 1 to 2 years after the attacks occurred. Such delays introduced risks of recall bias and delayed accumulation of evidence. In term of identifying and tracking potentially exposed individuals, there was a sizable, but unmeasured, overlap of participants from the rescue and recovery worker population across three of the programs. With the exception of the FDNY program, which assembled a complete cohort of active firefighters and voluntary screening for retired firefighters, the other programs resorted to mounting extensive public recruitment campaigns to encourage voluntary recruitment [28]. The lack of systematic tracking of responders during the rescue and recovery phase slowed recruitment efforts and introduced selection biases in enrollment [29].

Although first responders began presenting with health effects almost immediately after the attacks [30], the first scientific studies reporting respiratory health effects among directly exposed responders were not published until a year after the attacks. Respiratory health assessments of directly exposed community residents were not published until 2005 [27,31]. Since then, the accumulated body of literature has been fairly consistent in its characterization of respiratory health consequences from the 9/11 WTC attacks, although not all mechanisms are well understood to date. In sum, soon after being caught in the dust cloud from the towers collapsing, or being exposed to either the WTC pile or residual dust, most survivors and responders experienced a range of upper and lower respiratory symptoms [29,30,32,33]. Symptoms resolved within days or weeks for most but persisted for others, especially those with more intense dust exposure. Across different directly affected population groups, new adult-onset asthma diagnoses ranged between 8% and 12%, approximately three times higher than estimated background levels [33], and loss of pulmonary function has been documented in a cohort of firefighters using pre- and post-event spirometry readings [34]. Most symptoms or conditions occurred in the first year after 9/11 WTC attacks, although diagnoses were sometimes delayed [33,34]. No studies to date have demonstrated elevated rates of late-onset asthma or delayed loss of pulmonary function.

A number of factors impeded studies to understand early physical health impacts. First, federal funding for acute health effects research was not coordinated centrally in the first several years after the attacks and no mechanism to convene stakeholders were established to identify policy-relevant questions or prioritize addressing key gaps in knowledge. Programs and investigators also had limited incentives to develop comparable exposure and health outcome measurement tools across studies to facilitate cross-study comparisons. Rosters of workers who responded to the disaster were not maintained, nor were shift dates or durations monitored for objective exposure measurements. These gaps resulted in pervasive delays and introduced selection biases that have been challenging to address when interpreting analytic results [31].

As epidemiologic evidence on persistent health effects mounted, an active lobbying campaign was launched by stakeholder lobbyists for federal funds to support dedicated treatment programs.

However, once research findings were available, the political landscape between 2004 and 2007 influenced the translation of these findings into clear policies. Legal disputes between labor unions and NYC around responsibility for compensation contributed to a polarization of research efforts into camps perceived to be aligned with either one side or the other and thus reduced effective communication and collaboration between scientific teams. This adversarial environment delayed efforts to identify and critically understand consistencies, differences, and gaps between studies. In 2007, the NYC Mayor's Office convened an array of local scientists to form the Mayoral Medical Working Group, aimed at collectively interpreting findings from the growing body of WTC-related literature. Guided by epidemiologic principals, this interdisciplinary team developed a comprehensive website for services, translated epidemiologic findings for public audiences and information about WTC-related health issues and legislative activity ([www.9-11health.org](http://www.9-11health.org)) and drafted an annual report beginning in 2008. These resources and mechanisms were developed to improve communication between scientists and help policymakers and media journalists more readily access an up-to-date and comprehensive body of evidence when developing policy pertaining to clinical services and disability coverage.

### Mental health effects

An explicit goal of most terrorist acts is to inflict psychological harm, and indeed the psychological consequences of WTC attacks were large [35–37]. Epidemiologic studies have played a key role in determining the burden of acute and persistent mental trauma resulting from the WTC attack, identifying groups at elevated risk, determining the extent to which traumatized individuals receive appropriate mental health care, and understanding the impacts of co-occurring physical and mental health conditions. Methodological challenges affecting research on physical health effects also pertained to mental health effects research. One added challenge was the need to ascertain mental health impacts on distal populations living in other parts of NYC and across the nation.

A recent systematic review of epidemiologic studies of post-traumatic stress disorder (PTSD) among highly exposed individuals during the first 10 years after the 9/11 attack provides a number of insights into plausibly causal risk factors related to the development of PTSD such as time, proximity, and role in the WTC disaster. In most studies, survivors and direct victims of the attack had elevated rates of PTSD compared with less exposed individuals. Symptom severity was also worst for those closer in physical proximity to the WTC towers and those who lost a relative or property [38]. Estimated prevalence of PTSD symptoms among directly affected groups ranged from 12% to 23% during the first several years after event [33,39].

Among rescue and recovery workers, the type of job held in response to the WTC attacks influenced risk for PTSD, with high rates among construction, engineering, and sanitation workers [38,40] and among responders working outside of tasks they had been trained for [41]. Several studies also indicated that lay (nonprofessional) volunteers unaffiliated with recovery organizations had elevated risk for PTSD and unmet health care needs compared with volunteers affiliated with organizations [33,35,41]. Predisposing risk factors unrelated to the September 11 attacks include prior mental illness, prior or subsequent traumatic exposures, lack of social support, and low socioeconomic status.

Although much of the published research on WTC-related mental health consequences has focused on the burden of PTSD in those directly affected by or responding to the attacks, or who lost a loved one [38], a small body of studies suggest that the psychological impact and negative mental health consequences

may not only have been limited to directly affected individuals [6,38]. Although risks were greatly attenuated in the wider, indirectly-exposed general population, elevated PTSD symptoms were identified among women, individuals with prior mental health disorders, and those who viewed greater amounts of 9/11 television coverage [37,42].

The measurement of mental health service utilization and estimation of unmet mental health care needs postdisasters is particularly challenging, particularly given the known lack of capacity of the mental health care system at meeting “endemic” treatment needs outside of the context of a disaster. An early needs assessment conducted by the NYC Department of Health in October–November 2001 found that 40% of lower Manhattan residents reported symptoms suggestive of PTSD and many of the participants did not know about or have access to mental health services. Yet, only about a third of area residents had received supportive counseling [43]. Several weeks after the attacks, a large array of dedicated mental health programs was mounted under the name Project Liberty, which has since provided services to close to 1.5 million individuals since 9/11 [44,45]. Findings from analyses of service delivery data from the first year of Project Liberty suggested that crisis counseling services were adequate for the majority of persons using Project Liberty services, but that additional services would be needed for a sizable minority of individuals with intense exposure to the attacks or predisposing risk factors. A large random-digit dial survey of the general adult population living in the Greater New York Metropolitan area conducted in 2002 found only one-third of residents with a probable diagnosis of PTSD or depression sought help from a mental health professional 6 months after the attacks, suggesting potential unmet mental health need [14]. Subsequent surveys of directly-exposed individuals identified that survivors lacking social support were more likely to report continued unmet mental health care needs [46].

Studies examining the impact of co-occurrence of physical and mental health symptoms have only recently begun to be published and suggest that poor health outcomes in comorbid individuals were more severe than those experiencing physical or mental health symptoms [47,48]. Although further studies are needed to better understand the relationship between PTSD and clinical health outcomes, it is important that disaster-related registries collect sufficient mental health and psychological distress data to continue to determine the risk of the development of longer term negative health outcome based on or aggravated by PTSD [49,50].

### Long-term health effects research

Perhaps, the strongest potential contribution of epidemiologic studies to postdisaster policy development is to anticipate and prospectively build knowledge regarding potential long-term health outcomes from disasters, which often involves a complex array of exposures. By 2008, a broad consensus had been reached regarding short- and medium-term respiratory and mental health outcomes resulting from the WTC disaster [26]. Less clear has been longer term health concerns such as elevated cancer risks and to a less extent diabetes, cardiovascular disease, and impacts on childhood growth and development.

Regarding cancer, in July 2011, the CDC National Institute for Occupational Safety and Health (NIOSH) published the “First Periodic Review of Scientific and Medical Evidence Related to Cancer for the World Trade Center Health Program” [51]. This report reviewed literature on potential cancer-causing compounds that people were exposed to, and it concluded with the following statement: “Following the September 11, 2001 terrorist attacks, environmental sampling of the area around the WTC in New York City identified 287 chemicals and chemical groups....Some of the chemicals



identified through environmental sampling are known to be human carcinogens or are reasonably anticipated to be human carcinogens. These known or reasonably anticipated human carcinogens have been associated ... with a number of different types of cancers, such as lung cancer including mesothelioma; skin cancer; bladder cancer; hematopoietic cancers; testicular cancer; prostate cancer; and liver and biliary cancer."

The same report provided a comprehensive review of 18 9/11-related articles that had been published to date mentioning cancer; none were epidemiologic studies with comparison groups. Five discussed cancer but presented no quantitative information and only five of the remaining 13 studies were peer reviewed. Two of these, both published in 2005, predicted an increased risk because of potential exposures but did not examine cancer occurrence *per se*, [52,53]. Moline et al.'s [54] case series of eight WTC responders diagnosed with multiple myeloma was the only original science article with data on cancer occurrences. The authors concluded that these cases represented an increased incidence of multiple myeloma (a ratio of 8 cases observed/6.8 cases expected = 1.18). Multiple myeloma has been previously associated with occupational firefighting and specifically linked to exposure to benzene, but the observed results could have arisen from selection and detection biases.

Because of the long latency periods of most cancers, the era when incident cancers could be attributed to WTC-related exposures only recently began, more than a decade postdisaster. Just after the CDC NIOSH report was released, the first epidemiologic study published in 2011 by Zeig-Owens et al. [55] reported on the experience of 9853 firefighters enrolled in the FDNY WTC Health Program. They found a nonsignificant increase in the incidence of any cancer in WTC exposed firefighters compared with nonexposed firefighters (standardized incidence ratio, 1.2) and compared with the general population (standardized incidence ratio, 1.1). The study did not assess cancer rates by level of WTC-related exposure. A study by Jordan et al [56] that same year looked at cancer deaths occurring in the WTC Health Registry participants, but found no increase in cancer standardized mortality ratio compared with the general population. A subsequent 2012 study of New York State residents enrolled in the WTC Health Registry [57] found statistically significant increases in prostate cancer, thyroid cancer, and multiple myeloma among individuals involved in rescue–recovery work only. No relation with intensity of WTC exposure was observed. The first two cancers are susceptible to oversurveillance bias, but the authors found screening practices were non-differential between those with and without cancer. For multiple myeloma, neither prior nor subsequent occupational exposure to benzene was recorded, leaving open the possibility of selection biases. A more recent article by Solan et al. [58] published in 2013 compared cancer incidence in 20,000 rescue and recovery workers to that in the general population from September 2001 to 2008 and estimated associations between cancer and the extent of WTC-related exposure. Significantly increased SIRs were found for all cancers combined, and for thyroid cancer, prostate cancer, combined hematopoietic and lymphoid cancers, and soft tissue cancers. This study accounted for prior occupation. However, quantitative exposure measurements were based on self-report and were crudely constructed. When the cancers were restricted to only those diagnosed 6 or more months after enrollment, SIRs became nonsignificant for all sites except prostate and thyroid cancers.

One decade after the WTC attacks, in September 2012, the federal government amended the James Zadroga 9/11 Health and Compensation Act of 2010 [59] to provide medical coverage for certain cancers [60]. This policy decision was based heavily on recommendations in the CDC NIOSH report that "approximately 70

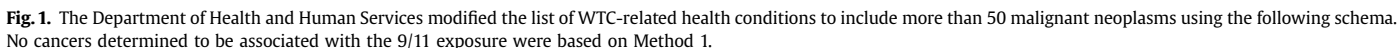
known and potential carcinogens" were identified in the dust cloud and contaminants and some exposed individuals had developed inflammation, a harbinger of future cancer development. A flow diagram of four potential methods was used by the CDC NIOSH-administered World Trade Center Health Program to decide whether to include a specific cancer for medical coverage under the Zadroga act (see Fig. 1). Based on the schema, the Department of Health and Human Services modified the list of WTC-Related Health Conditions to include more than 50 malignant neoplasms [61]. Method 1, the criteria most familiar to epidemiologists as being methodologically more reliable, was not invoked as a rationale for any of the listed cancers, reflecting the early state of evidence generation through epidemiologic studies, pervasive methodological challenges with respect to selection bias and exposure assessment, and the disconnect in timing between policymaking and scientific findings.

### Unmet health needs, disability and compensation

People who were injured or became ill as a consequence of the WTC attacks required care and potentially incurred two types of financial costs: (1) direct costs of medical treatment received and (2) indirect costs associated with losses of earnings capacity or related financial damages suffered. In the early aftermath of the WTC attacks, there were limited systematic efforts to determine exactly how many people had been or would likely become injured or ill, and whether they had appropriate coverage to meet their medical and mental health needs [31]. There was even less information about costs that affected people were incurring or might incur and only speculation about gaps in these pre-existing financial protection mechanisms. In some respects, the need policymakers would have for such information was overlooked by the majority of early epidemiologic efforts that focused on etiologic attribution. However, epidemiologic studies are also often the best source of information on the number of people affected and assessing which groups are receiving inadequate care. Although not always perceived as epidemiologic research, these data can directly inform policy decisions on how to structure and finance specialized services and often serve as important determinants of long-term health complications.

Existing funding mechanisms such as private and public health insurance, disability and workers' compensation programs provided some financial protection and compensation for many survivors and responders (see Table 1, existing programs). Private health care insurers paid for care; some people became newly qualified for federal disability insurance (<http://www.smjlegal.com/Success-Stories.shtml>, downloaded May 22, 2013); and the New York State worker's Compensation system received 11,627 WTC-related cases by 2009, including claims from about 3800 people injured after the attacks who had received an award for disability or medical claims by 2009 [62].

In addition to these existing mechanisms, policymakers also erected a series of WTC-specific financial compensation and regulatory mechanisms (Table 1, new funding mechanisms) that went beyond existing mechanisms in the extent of compensation provided or in the types of people eligible for compensation. Because neither uniformed workers nor volunteers, the two main groups of first responders, were routinely covered under the state workers' compensation system, these groups could not rely on this key social welfare mechanism without further regulatory action. The development of such WTC-specific compensation mechanisms placed new demands on epidemiologic findings about the extent of injury and illness that could be attributed to the WTC. To compensate specific individuals, findings about population-level relationships between exposures and incidence of disease, such as those



nature of problems covered meant that not even epidemiologic findings were used to provide compensation. Approximately 4200 VCF claims were filed by people who had sustained injuries that did not require immediate hospitalization [63]. The second significant stream of early special financing was aimed at extending access to mental health services; existing mental health services were recognized to be inadequate in terms of capacity and expertise to meet new needs. Federal Emergency Management Agency created a special program named Project Liberty to provide crisis counseling assistance and training for those affected by the attacks, and private

**Table 1**

Description of existing and newly created funding mechanisms to compensate people for treatment or consequences of 9/11-related health-related conditions, 2001–2012

Funding mechanisms	Program	Eligibility—population	Eligibility—conditions	Coverage	WTC related	Number compensated
Existing funding mechanisms	Private health insurance/Medicare	Most employed people and those aged 65+ years, including responders, residents, and victims	Illnesses and injuries that did not stem from employment	Mental and physical health care costs (except copayments)	No	Unknown
	Medicaid	Single adults with incomes <100% FPL	Illnesses and injuries that did not stem from employment	Mental and physical health care costs	Disaster-relief eligibility process	Unknown
	Employer-based short- and long-term disability insurance/supplemental security income/social security disability income	Employed people with coverage/low-income disabled people/people eligible for social security	Illness and injuries that cause disability	Partial wage replacement	No	Unknown
New funding mechanisms [1]	Workers' compensation extended through state law in 2005 and 2006 to cover volunteers and NYC employees	Employed people/WTC volunteers; fire department covered under similar	Illnesses and injuries that stem from employment	Mental and physical health care costs; wage replacement	Extended to volunteers and NYC employees; deadlines extended	3800 with illnesses and injuries occurring after the attacks
	WTC victim compensation fund	All persons killed or injured within 96 hours of the attack	Death or physical injury due to the attack itself	Economic and noneconomic losses	WTC specific	2680 persons injured during or immediately after the attacks
	Project Liberty/American Red Cross/Charity mental health services	All New Yorkers	Mental health symptoms	Mental health treatment	WTC specific	256,000 visits by 2002
	Captive insurance company	Persons who participated in the rescue and clean-up effort	List of defined conditions, including physical and mental health conditions	Monetary compensation	WTC specific	Approximately 10,000 persons who participated in clean-up compensated
	Zadroga Act	Responders and area residents	List of defined conditions, including physical and mental health conditions	Monetary compensation, treatment	WTC specific	ongoing

charities also provided significant funding for additional mental health services. Expansion of these services was based on epidemiologic findings from earlier disasters, which had found that such acts were associated with high incidence of mental health problems. Epidemiologic analysis of data from the WTC attacks themselves buttressed these earlier findings and lent support to continuation of these programs over time. Within a year of the attack, the American Red Cross had provided 236,000 mental health counseling visits and other private charities had funded an additional 20,000 visits; various programs continued through 2011 [63]. By contrast, some evidence suggests that private insurers actually saw a decline in mental health service use (about 15%–20% fewer visits) in the first several months after the attack [64].

The final component of special funding focused on compensation for those injured, particularly those harmed during the recovery effort. The allocation of these funds depended, throughout, on drawing inferences about individual cases (with varying symptoms, exposures, and co-occurring conditions) from epidemiologic findings about exposed populations. The timing of compensation, however, required that such inferences be drawn based on incomplete data. Congress first established a \$1 billion captive insurance company that would pay claims against the city related to these losses. By 2010, the city had been sued over 10,000 times by responders, and on March 11, 2010, these claims were settled for about \$700 million, based on an enumerated list of conditions that qualified for compensation, which was only loosely based on available scientific findings and focused mainly on symptom severity [65]. The 2010 legal settlement left the captive insurance company with relatively little funding to pay the costs of claims for injuries that might manifest later, it did not provide a

source for financing the ongoing costs of monitoring and treatment of victims, and it did not finance services provided to area residents or those exposed outside the workplace. In response, Congress passed the James Zadroga 9/11 Health and Compensation Act of 2010, (Pub. L. No. 111-347, 124 Stat.3623 [2011]), under which an additional \$4.3 billion was made available for medical monitoring, treatment, and compensation of responders and area residents physically harmed through the attacks. The act did not provide compensation for psychological injuries caused by the attacks. The Zadroga act made much more use of the now more robust epidemiologic findings, but the scientific basis for making compensation determinations for long-latency diseases (such as cancer) remained slim.

In sum, several new sources of disaster-specific funding sources were established in the aftermath of the WTC attacks by the federal, state, and city government and charitable organizations. In many cases, these new funding streams required some system of causal attribution. As described in the case of cancer, these systems proceeded mostly by identifying conditions that could plausibly be linked to the attacks and to the clean-up, rather than definitive population health study findings or on well-designed epidemiologic studies. The need to make determinations around compensation quickly was at odds with the reality that making good epidemiologic inferences requires collection and analysis of data over time. Moreover, the fact that flows of large sums of money depended on epidemiologic findings may have unduly politicized the scientific environment. Ideally, such a process would have relied on the expertise of epidemiologists to draw more careful population-level inferences about risks and harms, but time lags in initiating studies, and the methodological

limitations described earlier deterred the process of producing evidence for such causal attribution.

### Lessons learned

*Systematic tracking of the involvement and protection of first responders is an essential aspect of postdisaster epidemiologic research and should be integrated into disaster response plans*

These findings suggest that improvements in monitoring responder protection can be made in preparation for future disasters. Although it may never be feasible to identify and document all who respond to a chaotic disaster scene in the first hours after an event, efforts should be made to establish a perimeter as soon as possible and to begin tracking all responders on the site thereafter. Such improvements in responder registration were made during the Deepwater Horizon oil spill disaster in 2010, where NIOSH developed a prospective roster of more than 55,000 workers and volunteers partially in response to lessons learned from the WTC disaster. Some responders to Deepwater Horizon were identified by official safety training rosters before deployment, whereas others were added to rosters through an intensive effort made at worker staging areas in four states [66]. Furthermore, instituting measures to monitor the availability of appropriate PPE, proper training in its use, fit-testing of responders for respirator use, adequate respirator maintenance, and appropriate use of respirators once deployed, is important to assess the extent of adequate protection for disaster responders. Epidemiologic surveys are often the main source of data used to assess actual practices with respect to PPE usage and adherence. Yet even when it is possible to obtain information from workers and residents, the reported use (or likely nonuse) of protective equipment can suffer from misclassification and recall biases.

Another lesson is the importance of gathering time-relevant exposure information, and baseline physical and mental health status and prior occupational exposures of workers. At the onset of a disaster, first responders need to have unimpeded access and may not wish or be able to participate in surveys or collection of environmental or biological specimens for research. Often, exposure assessment is imputed through a combination of surveys, occupational lists, and statistical models. Measurement of exposures in the environment has been somewhat limited by the difficulty identifying accurate objective markers of exposure. Possible advances to address this might include having workers or responders wear radiation monitoring badges, carry electronic air sampling devices equipped with Global Positioning Systems capabilities, etc. New technologies bring promise of advancing the development of “exposimeters” for use in disasters, particularly those that tend to recur. Similarly, in the field of psychiatric epidemiology, experts increasingly recognize the need for longitudinal studies of disaster victims to monitor the trajectories of mental health outcomes and understand factors associated with different courses over time [11].

*Pre-event planning and early coordination of epidemiologic research can improve research design, coordination, and communication*

In the example of the WTC disaster response, acute health effects research was catalyzed by a strong local infrastructure for health research, including those with extensive experience in occupational and environmental health matters. Not all areas affected by a disaster have such depth of infrastructure and thus need to rely more on federal and regional partners. Yet despite the individual and collective strengths of the NYC institutions, none had robust predisaster protocols for rapidly mounting such studies in Fall 2001. Since then, more academic institutions across the country

and local, state, and federal agencies have started to develop specialized emergency IRB review mechanisms to allow expedited review of time-sensitive protocols developed immediately after a disaster [67] and National Institutes of Health has established a Public Health Emergency Research Review Board.

Mechanisms are also needed to allocate and disburse governmental and other funding resources for these early data-capturing efforts quickly, perhaps using sole source mechanisms or standby review teams to get money moving. Even with such mechanisms, however, academic teams may experience critical time lags in obtaining IRB approval for collecting early exposure information. In such instances, governmental partners—under the auspices of public health surveillance and response—may have authority to collect time-sensitive exposure data for subsequent use in collaborative research.

*Early identification of gaps in knowledge after a disaster can guide prioritization and deployment of research*

In the case of WTC disaster response, two key gaps in the early stages of research included (1) measuring the absolute unmet health needs and gaps in financial coverage and (2) planning for coordinated research to assess long-term health outcomes across the various cohorts. As a direct result of the lessons learned from response to the WTC attacks, other key steps have since been taken at the federal level to improve coordination and communication regarding health impacts and health effects research. After the Deepwater Horizon oil spill in 2010, for example, the Institute of Medicine convened two multidisciplinary workgroups at the request of the Department of Health and Human Services to guide health effects research. The first was an Emergency Responder Health Monitoring and Surveillance Interagency Workgroup, which drew on experts from around the country, to help identify how best to quickly track health impacts and what to measure. Among other things, this workgroup recommended that rescue–recovery worker roster information be collected prospectively in the context of disaster response rather than retrospectively, as occurred during the World Trade Center event 9 years earlier (<http://www.cdc.gov/niosh/docs/2011-175/>). The second workgroup was tasked to identify priority research questions regarding possible long-term health impacts. Similarly, at the request of Health and Human Services, following Hurricane Sandy, the New York Academy of Medicine, in collaboration with the Institute of Medicine, convened a stakeholder group to identify research gaps and priorities. Most recently, with respect to coordination of postdisaster research, leaders from the Department of Health and Human Services published a commentary recommending that an incident commander for scientific research be appointed to coordinate the process of research [68].

*Interplay between policymaking and scientific processes can be challenging and mistrustful. Developing mechanisms to interpret and communicate scientific finding to policymakers and the public may reduce mistrust*

In the wake of a disaster, science should and often does play a critical role in informing policy decisions. This process can be fostered and expedited by both scientific and policymaking institutions, respectively. Within academic communities, scientists—particularly those who are reticent to interact with legislators and regulating bodies—should be encouraged to share their findings, familiarize themselves with the pressing outstanding disaster-related questions, and identify potentially useful outcomes for policymakers [69].



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