

The Response to September 11: A Disaster Case Study

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ABSTRACT

Background: The response to 9/11 continues into its 14th year. The World Trade Center Health Program (WTCHP), a long-term monitoring and treatment program now funded by the Zadroga Act of 2010, includes >60,000 World Trade Center (WTC) disaster responders and community members (“survivors”). The aim of this review is to identify several elements that have had a critical impact on the evolution of the WTC response and, directly or indirectly, the health of the WTC-exposed population. It further explores post-disaster monitoring efforts, recent scientific findings from the WTCHP, and some implications of this experience for ongoing and future environmental disaster response.

Findings: Transparency and responsiveness, site safety and worker training, assessment of acute and chronic exposure, and development of clinical expertise are interconnected elements determining efficacy of disaster response.

Conclusion: Even in a relatively well-resourced environment, challenges regarding allocation of appropriate attention to vulnerable populations and integration of treatment response to significant medical and mental health comorbidities remain areas of ongoing programmatic development.

Key Words: disaster response, environmental disaster, 9/11, post-disaster health surveillance, World Trade Center

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INTRODUCTION

The response to 9/11 continues into its 14th year. More than 60,000 World Trade Center (WTC) responders and community members (“survivors”) participate in the World Trade Center Health Program (WTCHP), a long-term monitoring and treatment program now funded by the Zadroga Act of 2011. Here we review key aspects of the response to 9/11 that have affected the health of the exposed population, subsequent monitoring efforts,

recent scientific findings from the WTCHP, and some implications of this experience for ongoing or future environmental disaster response.

THE IMMEDIATE RESPONSE TO THE WTC DISASTER: COORDINATION AND SITE SAFETY

The extremely chaotic conditions at the WTC site challenged the coordination of rescue and recovery efforts there. The New York City Office of Emergency Management (OEM), headquartered at the WTC, lost its entire command center. This was a major blow to the city’s overall emergency response. The OEM was the intended coordinator of emergency response among ~150 agencies. OEM employees were forced to evacuate in the early hours of the disaster. Many telephone, power, and computer lines were down. The police had closed off lower Manhattan, making it difficult for officials to get past checkpoints without badges.

These circumstances also complicated the federal government’s ability to respond to environmental and safety concerns. The Federal Emergency Management

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All authors declare they have no conflicts of interest

Research reported in this article was supported by a contract with the National Institute of Occupational Safety and Health (NIOSH). Contract number: 200-2011-39356

Conflict of Interest statement for all authors: None of the authors of this manuscript have conflicts of interest to report.

<http://dx.doi.org/10.1016/j.aogh.2014.08.215>

Administration (FEMA) and the Environmental Protection Administration (EPA) were tasked with coordinating the overall rescue and recovery efforts.¹ These agencies faced extraordinary difficulties. EPA's regional office, about half a mile from the WTC site, was evacuated and not reopened until 2 weeks after the attacks.² Transportation to Lower Manhattan was halted, as was commercial air travel nationwide.

The search and rescue operation at Ground Zero was initially under the direction of the New York City Fire Department (FDNY). Subsequently, it became a recovery operation under the jurisdiction of the New York City Department of Design and Construction (NYCDDC) along with the FDNY. According to an FDNY report³ “the complexity of the activity performed at one site—rescue, recovery, demolition, and construction—at one time is unprecedented.” The convergence of multiple elements helps explain the unique challenges of the WTC disaster: the sheer scope and scale of the incident in a concentrated geographic area, its nature as a terrorist attack, the environmental destruction, the physical devastation, the financial effects globally and locally, the involvement of multiple agencies, and the international scope of its ramifications.²

Risks for Workers and Residents at the WTC site

Many key recovery functions had significant environmental, safety, and public health implications for the responders involved: firefighting, urban search and rescue, recovery of crime scene evidence, medical emergency care, public works (debris removal, construction, and demolition), traffic control, public health (sanitation, control of dust inhalation, isolation of dead bodies, or the injured), removal of hazardous materials, and mortuary operations. The earliest responders to the WTC attacks were trained FDNY, Port Authority and New York police personnel. Unfortunately, many other responders, such as construction, demolition, ironworkers, electricians, volunteers, and cleaners, had never been trained or advised to use proper personal protective equipment, nor educated about the potential hazards at Ground Zero.

An October 2001 report by the National Institute of Environmental Health Sciences discussed construction workers' safety issues at the WTC site for the period up to October 5, 2001.⁴ According to the report:

- Respiratory protection was rare with the exception of heavy equipment operators. Workers were observed in the smoke plume emanating from the pile without hard hats, eyewear, or respirators.
- Workers did not decontaminate after leaving the site. The hand/face and boot wash stations did not appear to be used by most of the workers.
- During the September 22-26, 2001 period, an increase in worker protection was observed, notably respiratory

protection. Hosing down the vehicles leaving the site finally began.

- There was no evidence that any safety and health programs were operating at the site. Various support personnel, workers, and government officials confirmed the lack of an operating safety and health program.

A January 2002 report prepared by a certified industrial hygienist for the Operating Engineers National Hazmat Program noted that during the period October 2-16, 2001, less than half of the heavy equipment operators regularly used respirators when working on the “pile” at Ground Zero, and often this use decreased to less than one-third of the workers.⁵

The absence of site-specific hazard training and a uniform health and safety plan greatly increased the vulnerability of those with less experience with hazardous work or rescue and recovery. Debchoudhury et al. studied 4974 adult volunteers who completed the WTC Health Registry 2006-2007 survey to examine associations between volunteering and mental and physical health consequences.⁶ They contrasted the outcomes for affiliated volunteers, who reported membership in a recognized organization with lay volunteers, who reported no organizational affiliation and occupations unrelated to rescue and recovery work. Among the lay volunteers were members of church groups or community organizations and individuals present in the area immediately following the attacks. Most were untrained and had no rescue and recovery experience. The authors found that lay volunteers were more likely than affiliated volunteers to have been present in Lower Manhattan, to have been exposed to the dust cloud, and to have witnessed horrific events such as watching bodies fall from the towers. They were more likely to have had an injury on 9/11 and subsequently to report unmet health care needs. They had greater odds of an early post-9/11 mental health diagnosis, asthma or reactive airways dysfunction syndrome, chronic post-traumatic stress disorder (PTSD), late-onset PTSD, and new or worsening lower respiratory symptoms. The authors concluded: “The experience of both professional and volunteer responders to 9/11 indicates a need for the provision of site-specific training, regardless of prior disaster experience, to limit exposure to specific hazards and familiarize volunteers with safe operating procedure.”⁶ Unprotected, untrained workers become another vulnerable population, and may increase the vulnerability of the community by poor handling and disposal of toxic materials.

Poor coordination of agency efforts at the WTC site, with the consequent failure to develop and enforce a health and safety plan and educate workers as to site hazards and required protection vastly increased health risks to WTC responders. This failure to implement basic operations and safety standards—such as site control, exclusion of untrained personnel from hazardous

areas, and keeping a roster of personnel—has had profound impact on the lives and health of WTC responders. From today's perspective, the lack of knowledge of who was on site is doubly tragic: Without complete ascertainment of the participating responder population, the full number and kind of illnesses related to the WTC exposure will never be known.

The full significance of the WTC exposure and the threat it posed to the exposed population would not have been recognized and reported without the prompt action of trained, experienced specialists in occupational and environmental medicine, industrial hygiene and public health who recognized the danger and joined with worker organizations to bring it to national attention. As recounted by Herbert et al.,⁷ increasing reports of illness occurring among responders within weeks of 9/11 at the WTC disaster site caused concern among community leaders. Local labor unions became increasingly aware that their members were developing respiratory and psychological problems. They initiated a campaign to educate local elected officials about the importance of establishing an occupational health-screening program. Occupational medicine physicians at Mount Sinai's Irving J. Selikoff Center for Occupational and Environmental Medicine (COEM), who had previously treated many such workers, recognized the potential risk of this exposure, and joined the educational effort. Skilled medical professionals at the FDNY and other agencies began evaluation and treatment programs for their employees.

In April 2002, the National Institute for Occupational Safety and Health (NIOSH) awarded the COEM at Mount Sinai a contract to establish and coordinate a medical screening program for responders. At roughly the same time, a collaborative effort by the New York City Department of Health and Mental Hygiene, and the federal Agency for Toxic Substances and Disease Registry (ATSDR) established the WTC Health Registry, an epidemiologic "database for following people who were exposed to the disaster of 11 September 2001."⁸ There was not yet any formal recognition of need or funding for WTC-related health effects experienced by local residents, workers, and students in the WTC area.

OUTREACH

Exposed WTC Workers⁹

COEM conducted an intensive outreach campaign that included development of written materials, participation in hundreds of meetings with unions and other responder organizations, public service announcements in English and Spanish, and an extensive media campaign and other strategies to increase awareness of the program throughout responder communities.

A critically important facet of the screening program was the participation of worker representatives in its

overall direction.⁷ An executive steering committee (ESC) was established; the ESC included representatives from each of the consortium clinics, representatives from labor unions, employers, and technical experts from relevant fields, and constituted an important line of communication directly to the responder population. Worker representation and outreach to labor and other organizations have remained a constant throughout the history of the WTCHP. From the very outset, this public health response sought to carry out its functions transparently and to establish a bond of trust with the exposed population.

The Population Living and Working Near the WTC Area Disaster Site

Unfortunately residents of the neighborhoods around the WTC site had a very different experience from the responders. Outreach to, and involvement of, the local residents, workers, students, and some of the cleanup workers (initially called "nonresponders" and currently "survivors") was characterized less by proactive governmental overture and more by determined efforts of the community to have its needs included in program development. Because of initial EPA assertions that the environment was safe, most workers returned the following week to inadequately cleaned or recontaminated buildings. Students and residents returned to contaminated buildings, often cleaning apartments themselves. There was never a baseline screening conducted, nor was a comprehensive cleanup of local residences and offices undertaken.¹⁰ The failure of local and federal authorities to conduct an aggressive and appropriate cleanup of Lower Manhattan, or even a comprehensive educational campaign, exposed the community to unnecessary health risks.

In 2001, New York University and Bellevue Hospital physicians collaborated with the New York State Department of Health to design to implement a study of local residents. The WTC Residents Respiratory Health Study sought to assess the onset of post-9/11 respiratory symptoms in previously healthy residents, given the strong probability of toxic exposures.¹¹⁻¹³ Efforts at community-level collective efficacy¹⁴ resulted in the formation of the Beyond Ground Zero Network (BGZ) by coordination of community-based organizations. BGZ started surveying vulnerable populations including immigrants and those in low-income communities. Multiple organizations including 9/11 Environmental Action organized environmental summits, and applied public pressure throughout late 2001 and 2002 through community board meetings, public hearings, and other advocacy efforts. This common action resulted in strong bonds of trust among physicians, public health professionals, and community members.

As no governmental program materialized, the BGZ reached out to Bellevue Hospital, where the Asthma Clinic began a pilot program for residents with presumed WTC-related illness. The program's results prompted a 3-year

American Red Cross Liberty Disaster Relief fund grant supporting its expansion in 2005 to a treatment program. Funding was subsequently obtained from the City of New York and, in 2008, federal funding was provided for a treatment program for local residents, local workers, students, and cleanup workers. This program, now called the WTC Environmental Health Center (EHC), is the only center of excellence funded for treatment of community members. A Community Advisory Committee (CAC) of the WTC EHC developed, reflecting the robust community mobilization and cooperation after 9/11. The CAC, which evolved into the EHC's Steering Committee, provided a forum for substantive input by community representatives and individuals, a continued advocacy that contributed to expansion of the WTC EHC program to include children in October 2007.¹⁴

A critical lesson learned from the 9/11 experience is the importance of recognizing that vulnerability extends beyond the responders to community members who were either unaware of the level of toxicity or, because of socioeconomic variables, could not avoid it. The sense of disenfranchisement by vulnerable cohorts has since been addressed in other disasters with such models as the Communities Advancing Resilience Toolkit. Interventions such as this, designed to support community resilience by including stakeholder input early on, recognize impact in 4 interrelated domains:

1. Connection and caring;
2. Resources;
3. Transformative potential; and
4. Disaster management.¹⁵

EXPOSURE ASSESSMENT: ACUTE AND CHRONIC

The intense fires in the WTC towers and their subsequent collapse created a 6-story pile of rubble ("The Pile") that burned intermittently for >3 months. The initial fire from the exploding aircraft rose to a temperature of 1000°C.¹⁶ The collapse of the WTC towers and nearby buildings spread 1.2 million tons of pulverized building materials—concrete, sheet rock, gypsum, fiberglass, plastics, asbestos, metals, glass, and their toxic combustion products—over a 16-acre disaster zone. The dust cloud released by the collapse engulfed Lower Manhattan, choking those caught in its path and contaminating residences and offices^{16,17} The aerosol plume from the site dispersed soot, metals, volatile organic compounds VOCs, hydrochloric acid, and other toxic chemicals over Lower Manhattan, Brooklyn, and miles beyond.

In the subsequent days, weeks, and months, air sampling was performed near the WTC site. The EPA, Department of Health and Mental Hygiene, and ATSDR collected air and dust samples from Lower and Upper Manhattan as a comparison. Airborne concentrations of asbestos were generally found to be very low. Concentrations

of metals and volatile organic compounds were also generally low. Lower Manhattan had higher percentages of fiberglass, mineral components of concrete, and mineral components of building wallboard in settled surface dust than the Upper Manhattan comparison area.¹⁸

Exposure assessments were limited by the few available measurements of the resuspended particles, the sampling delays, the variation of components of the substances released over the initial days and months, and the differences in patterns of contact. As such, what is known about the composition of the dust cloud is based largely on the analysis of samples of outdoor and indoor settled dust.¹⁷ The caustic, alkaline large particles and large fiberglass fibers present in WTC dust are likely responsible for its irritant quality.¹⁹ In the absence of precise acute exposure data, surrogate markers of exposure such as "caught in the dust cloud" and "total time spent working at the site" have demonstrated a dose-response relationship to decrements in physical health and function.²⁰⁻²² Additionally, animal models have demonstrated the toxicity of WTC dust. Mice exposed to WTC dust show marked bronchial hyperreactivity.²³ More recently, a study that exposed rats to WTC dust suggested the carcinogenicity of its contents.²⁴

For residents of Lower Manhattan, chronic exposure to dust in homes and workplaces has been associated with lower respiratory symptoms in a dose-dependent manner. Variables such as the extent of surface dust coverage and depth of thickest dust layer²⁵ are positively associated with occurrence of symptoms. One survey¹³ revealed that residents who lived near the WTC on 9/11 had significantly more upper respiratory symptoms. The incidence of new lower respiratory symptoms in previously healthy nearby residents was greater than that in residents of the control area. Community members in the affected area also endorsed persistence of their symptoms.

Such detailed assessments of exposures during and after a toxic release, and rapid intervention to minimize their impact, are critical to the prevention of adverse health effects. As noted previously, the responsible agencies did not systematically carry out these assessments or appropriate preventive interventions either at Ground Zero or in Lower Manhattan after the WTC disaster. This inaction increased the health risks associated with WTC disaster exposure for both responders and members of the local community.

HEALTH IMPACT ASSESSMENT

Respiratory

Before September 11, 2001, spirometry was performed every 1 to 2 years on all FDNY firefighters. Therefore, baseline data on this group of rescuers was available to compare with their lung functions after their exposure to WTC dust. One study evaluated 332 FDNY

firefighters with severe cough and other respiratory symptoms after WTC exposure. The study found that intensity of exposure was related to prevalence of both respiratory symptoms and bronchial hyperreactivity.²¹ Over the longer term, another study compared firefighters' average spirometric values during the first year post-9/11 with values in the 5 years before 9/11. WTC-exposed firefighters experienced a reduction in adjusted forced expiratory volume (FEV₁) of 372 mL in the first year after 9/11, equal to 12 years of aging-related FEV₁ decline. The decrease in function was related to arrival time at the WTC site and the intensity of WTC exposure.²⁶ It has been demonstrated that this loss of function could last >6 years.²⁷ Another study found that airway obstruction was the most common cause of the decrease in function.²⁸ It also has been demonstrated that persistent symptoms over 4 years after 9/11 were related both to early arrival and longer duration of work at the WTC site.²⁹ The respiratory symptoms in the FDNY disaster workers demonstrated some improvement over time. The relationship between lung function and confirmed lower respiratory symptom recovery was examined in a survey of WTC-exposed firefighters between 2001 and 2010. Almost 35% of initially symptomatic individuals reported complete recovery in the follow-up period 7 to 9 years later. Confirmed lower respiratory symptom recovery was least likely in firefighters who were caught in the dust cloud at the WTC disaster site on the morning of 9/11 and more likely to occur in never smokers. Higher FEV₁ measured shortly after 9/11 and improvement in FEV₁ since immediately after 9/11 were both predictors of confirmed lower respiratory symptom recovery up to 9 years after the attacks.³⁰ This remarkable series of studies draws heavily on pre-exposure spirometry findings and demonstrates the critical importance of pre-existing data from routine medical evaluations for WTC rescue and recovery workers.

Other early surveys elicited respiratory symptoms occurring after the disaster among police officers and iron workers, revealing common complaints of dyspnea, chest tightness, and cough that were new or worsening. Lower respiratory diseases in the various WTC disaster workers have been categorized as irritant-induced asthma, chronic nonspecific bronchitis, chronic bronchiolitis/small airway disease, aggravated pre-existent chronic obstructive lung disease, eosinophilic pneumonia, granulomatous pneumonitis, and sarcoid-like disease.³¹⁻³³ In a WTC Health Registry survey conducted between 2003 and 2004, the 3-year incidence (3.6%) of newly diagnosed asthma post-9/11 was 12 times higher than the expected incidence (0.3%) in the general adult population.³⁴ In a study of a large cohort of WTC rescue and recovery workers including 27,449 police officers, firefighters, construction workers, and municipal workers, results showed that 9 years after the 9/11 WTC attacks, the cumulative

incidence of asthma was 27.6%.³⁵ Risk factors associated with asthma diagnosis in the WTC cohort included being a rescue and recovery worker; working on the debris pile; and returning to homes and offices covered with a heavy layer of dust after the evacuation following the 9/11 disaster. Other predictors of asthma in the WTC cohort were arrival at the WTC site within 48 hours of the attack; past or present cigarette smoking; and either lack of respiratory protection or delay in the initial use of masks or respirators.³⁴⁻³⁷

New-onset asthma also has been observed in children exposed to WTC dust. The highest risk was found in children under the age of 5 who were caught in the cloud. Children with dust cloud exposure have experienced a reduction in FEV₁/forced vital capacity (FVC) and subnormal FVC and FEV₁, displaying an obstructed pattern and low vital capacity.³⁸ Much more research is needed on the health effects of 9/11 on children.

These published, peer-reviewed health impact assessments clearly benefit injured disaster workers as they assist health providers in understanding the cause, nature, and extent of the rescuers' injuries. Additional information about impact on exposed children and adults in the community would have been similarly beneficial. However, assessments and surveillance for survivors and children were carried out less frequently than assessments for occupational exposures. These assessments foster continued medical surveillance, which in turn can more fully characterize WTC-related diseases, enable further research, and over the long term, improve the treatment course for the injured.

Mental Health

The WTC disaster presented a complex picture of both terrorist attack and environmental disaster, and this compounded impact deeply influenced the nature of subsequent related mental health issues. In a disaster, the immediate goals are to reduce distress, address exacerbations of predisaster psychiatric illness, and prevent the onset of new psychiatric illness.³⁹ A number of studies highlight the mental health problems that have been prevalent in the rescue and recovery workers, along with various risk factors.

Psychiatric disorders associated with trauma exposure include PTSD, major depressive disorder, generalized anxiety disorder, panic disorder, and substance use disorders. Additionally, a common comorbid disorder with PTSD is borderline personality disorder, which is understood often to be due to multiple and repetitive traumas early in life. Trauma affects the development of characterologic vulnerabilities that can lead to both borderline personality disorder and PTSD.⁴⁰

Respiratory conditions such as asthma are also comorbid with PTSD, depression, and anxiety. Theories attempting to explain this association postulate that PTSD may be associated with immunologic dysregulation, leading to pulmonary inflammation and autonomic

dysregulation; that chronic respiratory symptoms are a constant reminder of the trauma that was experienced, leading to elevated PTSD rates; or that the comorbidity is coincidental and both are due to the same exposure.⁴¹ Despite the mental health problems that are prevalent in a disaster, it is important to note that resilience is the most commonly observed reaction. It has been reported that 76.2% of WTC Registry enrollees, both 2 and 6 years after the 9/11 attacks, did not screen positive for PTSD symptoms.⁴²

Risk factors for mental illness after a disaster include prior trauma, prior mental health problems, female gender, and younger age. Other significant factors associated with psychopathology after a disaster include low socioeconomic status, minority ethnicity, and few social supports.⁴³ Manhattan residents enrolled in the registry who lived south of Canal Street at the time of the attacks had a 12.6% prevalence of probable PTSD. Vulnerability was associated with older age, female gender, Hispanic ethnicity, lower education and income, and divorce. Chronic PTSD was associated with injury, witnessing horror, and dust cloud exposure on 9/11.⁴⁴ For rescue and recovery workers, PTSD rates ranged from 6.2% for police to 21.4% for unaffiliated volunteers. The greatest risk for developing PTSD among the first-responder population was identified in construction workers, sanitation workers, and unaffiliated volunteers. Earlier start date and longer duration worked were significant risk factors for all except police responders.⁴⁵

The 9-year cumulative incidence of PTSD in police responders was reported to be 9.3% and 31.9% in other rescue and recovery workers. Depression was reported at 7% and 27.5% respectively, with panic disorder at 8.4% and 21.2%, respectively.³⁵ Probable PTSD was observed in 11.1% of rescue and recovery workers and a substantial stress reaction in 45%.⁴⁶ PTSD was associated with loss of family or friends; disruption of family, work, and social life; and higher rates of behavioral symptoms. Social impairment was elevated more than 17-fold among those with PTSD compared with those without probable PTSD. Of 2960 utility workers 10 to 34 months after 9/11 who were evaluated by the Clinician-Administered PTSD Scale (CAPS) and completed the PCL, 8% met criteria for full PTSD, 9.3% for subsyndromal PTSD, 6% major depressive disorder, 3.5% generalized anxiety disorder, and 2.5% for panic disorder. Prior trauma and psychiatric history were predictors of developing PTSD. The best predictor of PTSD in this population was subjective perception of threat to life. In this sample, number of days at the site, a standard exposure variable, did not predict probable PTSD.⁴⁷

Police responders share the burden of PTSD symptoms as well. Of 8466 police officers who completed an initial evaluation assessing symptoms (PCL-S), 5.4% met criteria for PTSD and 15.4% for subsyndromal symptoms. Subsyndromal symptoms have been demonstrated to be associated with elevated rates of

comorbid disorders, functional difficulties, somatic symptoms, and perceived mental health care need.⁴⁸ A longitudinal study of the police responders showed that more met criteria for probable PTSD 6 years post-9/11 (16.5%) than 2 years after (7.8%). Although an increase in PTSD symptoms over time post-disaster is unusual, a number of factors were related to the increase in this police sample, which included male gender, responding to the study by mail/Web, loss of job after 9/11, and being disabled.⁴⁹ Of 11,006 firefighters who completed questionnaires during the 9 years status post-9/11, those who arrived on the morning of 9/11 had the highest prevalence of PTSD in all years, which was at 13.4% by year 9. Of the 807 firefighters who met criteria for probable PTSD in year 1, 87.7% recovered at some point during the 9-year follow-up.

Those who reported a decrease in exercise due to health reasons had a lower likelihood of recovery from probable PTSD. Each additional respiratory or digestive symptom was associated with an 11% lower likelihood of recovery from probable PTSD.⁵⁰ Of FDNY retirees from 2005 to 2007, 23% screened positive for elevated risk for depression and 22% for elevated PTSD risk. Specific risk factors for depression in this group included problematic alcohol use, and the PTSD risk factor was early arrival at the WTC site.⁵¹

Exposure to trauma can lead to substance misuse, an area of research affected in part by stigma and potential employment impact. In a survey of New York City residents who experienced the 9/11 attacks, alcohol use increased over time among those with later or delayed-onset PTSD, leading to the hypothesis that those with increased alcohol use were attempting to regulate symptoms.⁵²

Other recent findings speak to the need for ongoing, comprehensive mental health treatment, and the barriers to receiving it. Unmet mental health care need (UMHCN) is a construct that describes either choosing care but not receiving it due to barriers, or not receiving expected care. In a sample of 46,226 individuals, enrolled in the WTC Health Registry, who were exposed to the 9/11 attacks and its aftermath, 4.2% reported UMHCN.⁵³ Those with UMHCN had more poor mental health days, fewer sources of social support, and a very high level of 9/11 WTC exposure. UMHCN was highest among individuals ages 19 to 29 with incomes <\$25,000. This complements the finding of another study that showed that those with probable PTSD or depression who sought mental health services had an annual household income of \$30,000 to \$75,000 and had a mental health problem before 9/11.⁵⁴ Barriers to care after 9/11 included lack of health program visibility and accessibility, stigmatization of mental illness, lack of referrals from primary care providers (PCPs), and reluctance to link symptoms to the terrorist attack because of lack of knowledge.

A high proportion of WTC responders with mental health conditions have comorbid physical conditions

that are exposure-related as well. Asthma and post-traumatic stress symptoms are 2 of the most commonly reported health outcomes seen since 9/11. Risk factors for WTC Health Registry enrollees who developed new-onset asthma and post-traumatic stress symptoms included acute and intense exposure as well as prolonged exposure.⁴² Lower respiratory symptoms have been reported to be associated with probable PTSD; however, abnormal lung function was not significantly associated with PTSD.⁴¹ Lower respiratory symptoms and probable PTSD 5 to 6 years after 9/11 co-occurred in 24.6% of residents, office workers, and passersby enrolled in the WTC Health Registry. Comorbidity was higher among those with more severe exposure. Those in the comorbid group had worse quality of life and more unmet mental health care needs than those in either group alone.⁵⁵ Of 10,943 FDNY firefighters and personnel, 41.8% of those with probable PTSD self-reported an obstructive airway disease (OAD) diagnosis. Of those with probable depression, 33.1% self-reported an OAD diagnosis, and 33.3% of those with probable PTSD or probable depression self-reported an OAD diagnosis.⁵⁶ Many patients also suffer from a triad of mental health, respiratory, and gastrointestinal conditions.³⁵ These comorbid disorders present challenges to those in need of mental health care, and speak to the need for comprehensive integrated care. Over time, adjustment disorders to new or progressive medical problems present as new or comorbid mental health issues for those with WTC-related and other medical problems.

Psychiatric comorbidity may be reduced by training emergency response staff to carry out traumatizing tasks before a disaster as well as limiting lengths of shift and total duration of work.⁵⁷ Risks factors for responders and volunteers for PTSD post-9/11 included early arrival at the site and working for more than 3 months at the site. There is also evidence correlating initial panic symptoms and subsequent psychopathology, suggesting that interventions addressing initial emotional responses may help prevent long-lasting symptoms.⁵⁸

Disasters also affect the mental health of children, but studies of children were very limited in the years after the 9/11 disaster. As with adults, substance use increased: In one large study, “students with one WTC exposure risk factor had a five-fold increase in substance use, while those with 3+ exposure risks had a nearly 19-fold increase,” manifesting with impaired school performance.⁵⁹

The potential for intergenerational transmission of trauma is also recognized, also with limited research since 9/11. One study demonstrated that concurrent maternal depression and PTSD was associated with increased emotional reactivity and aggressive behavioral problems in preschool children, particularly boys, 3 years after the WTC attacks.^{60,61} But as with physical health, research into the mental health effects of 9/11 on this very vulnerable group has been infrequent.

Much of the research on mental health after disasters focuses on mental health rates from screening assessments and on mental health utilization or barriers to treatment.⁵³ The evidence base for treatment recommendations of PTSD in first responders has rightly been described as “startlingly sparse.”⁶² The same can be said for the general community population, where chronic PTSD and multiple mental health and medical comorbidities confound usual inclusion criteria for clinical trials. Further research in these areas is critical for the ongoing care of the WTCHP population.

DEVELOPMENT OF A FEDERAL PROGRAM FOR MANAGEMENT OF LONG-TERM DISASTER IMPACT

In 2010, the US Congress passed the James Zadroga 9/11 Health and Compensation Act, creating the current WTCHP. The WTCHP offers medical monitoring examinations and treatment of WTC exposure-related illness to rescue and recovery workers (“responders”) and treatment, but not monitoring, to symptomatic members of the local community (“survivors”). The services are available through 7 clinical centers of excellence in the New York City metropolitan area and through a national program. The Zadroga Act funds the WTC data centers, which process and store clinical information, and the longitudinal study of the WTC-exposed populations conducted by the WTC Health Registry. The Act established the director of NIOSH as WTCHP administrator, created a list of WTC-related health conditions for which treatment is available, and provides funding for research into WTC-related physical and mental conditions. The WTCHP’s structure promotes responsiveness to the unmet clinical needs and health risks of the WTC-exposed population, which may be discovered during the long-term monitoring process.

The Zadroga Act also identified a process through which the WTCHP program administrator may identify medical conditions that should be added to the list of WTC-related conditions. The administrator may request a recommendation by the WTC Scientific/Technical Advisory Committee (STAC) on adding a condition. The STAC consists of physicians in occupational, pulmonary, and environmental medicine or environmental health specialists, representatives of WTC responders, and certified-eligible WTC survivors; an industrial hygienist, toxicologist, epidemiologist, and mental health professional.^{63,64}

The Zadroga Act specifically requires reviews of the scientific evidence relating cancer to WTC exposure. This concern was prompted by environmental assessments that demonstrated that the dust generated after the attacks included known and suspected human carcinogens, such as asbestos, silica, benzene, polychlorinated biphenyls, polycyclic hydrocarbons, VOCs and numerous metals. However, the STAC may review any

medical or scientific evidence and provide recommendations to the WTCHP administrator on inclusion of any additional health conditions in the program.^{20,63,64}

A 2011 study of cancer incidence in FDNY firefighters triggered a STAC cancer review. The study noted a 10% increase in standardized incidence ratio (SIR) for cancer at all sites compared with the general male population in the United States with similar demographics. Additionally, a 32% higher SIR was observed in WTC-exposed firefighters compared with nonexposed firefighters for cancer at all sites.⁶⁵ The study also found an increased SIR for non-Hodgkin lymphoma and thyroid and prostate cancers. Subsequently, another study found that of the 55,778 New York State residents enrolled in the WTC Health Registry, 1187 had been diagnosed with cancer.⁶⁶ The study also observed an increased SIR for thyroid cancer, prostate cancer, and multiple myeloma.⁶⁶ A third study of 20,984 responders found that 552 responders were diagnosed with cancer. Results from this study showed a 15% increase in cancers at all sites combined and an increased SIR for all hematologic cancers combined and thyroid and prostate cancers.⁶⁷

In response to the findings of increased cancer rates, the WTCHP administrator requested that the STAC “review the available information on cancer outcomes associated with the exposures resulting from the September 11, 2001, terrorist attacks, and provide advice on whether to add cancer, or a certain type of cancer, to the List specified in the Zadroga Act” of WTC exposure-related conditions. The WTCHP STAC was tasked to perform detailed literature reviews of individual cancers and available WTCHP data from the FDNY, Responder, Survivor and Registry programs and determine the likelihood of a causal link to WTC exposure.

In 2012, the STAC committee reported that there was sufficient evidence to support a causal link between specific cancers and exposure at the WTC disaster site.²⁰ The final ruling added specific cancers to the already existing WTCHP-covered condition list and allowed for funding of diagnosis and treatment services for these cancers.

The addition of cancer as a WTC-related condition demonstrates the WTCHP’s adaptability to cover conditions and health risks that may arise decades after the initial exposure. The development of the STAC was a crucial step in providing a forum for discussion and updates in WTCHP scientific developments.^{63,64}

ONGOING EPIDEMIOLOGIC ASSESSMENT: THE WTC REGISTRY

The WTC Health Registry “was established to prospectively monitor the physical and mental health of persons with a high probability of direct exposure to the September 11 terrorist attack and its aftermath, including rescue/recovery workers, persons with a primary residence in lower Manhattan on September 11, and office workers

and passersby present in lower Manhattan on the morning of September 11.”⁴² The Registry has recruited >70,000 participants. Since 2003, it has conducted repeated “waves” of either computer-assisted telephone or in-person interviews with this population. Wave 1, for example, included questions concerning demographics, event-related exposures, and pre- and post-event physical and mental health. Wave 1 interviews were conducted from September 2003 through November 2004; 95% were conducted using computer-assisted telephone interviews, and the remainder used computer-assisted in-person interviews.⁴²

The WTC Registry has published dozens of epidemiologic analyses of the WTCHP population, describing, among other issues, the incidence of respiratory illnesses, mental health conditions and comorbidities, and overall mortality. These studies reveal important new data about the WTC-exposed population, while also monitoring program outcomes. The previously mentioned investigation of unmet mental health needs assesses both the health status of the population and evaluates the WTCHP’s overall effectiveness in meeting the population’s mental health care needs.

A 2012 journal article described how the Registry used such information to modify and improve its performance, and the performance of the WTCHP.⁶⁸ The problem addressed by the authors was the lack of utilization of WTC medical and mental health services at the WTC EHC by the survivor population. The EHC clinical center of excellence was designed as an integrated medical and mental health program for the community. By 2009 the Registry had developed a Treatment Referral Program (TRP) to assist survivors with the scheduling of EHC visits. The Registry noted that, “despite widespread outreach efforts, including media campaigns, subway ads, and mass mailings by the EHC, the Registry, and a coalition of community-based organizations, only a small proportion of survivors have utilized services available at the EHC. For this reason, the TRP initiated personalized outreach to encourage enrollees and others with 9/11-related physical or mental health conditions to seek 9/11 specialty care at the EHC. Early interactions with enrollees revealed their limited knowledge of available 9/11 services and numerous barriers to care.”⁶⁸

The authors conducted 6 focus groups with enrollees, assessing both the participants’ knowledge about existing WTCHP health services and barriers preventing participants’ utilization of those services. The enrollees’ participation in WTCHP medical and mental services was generally low. The groups discussed barriers to care, symptoms and their relationship to 9/11 exposure, and WTCHP services and utilization. Enrollees described a variety of symptoms, and numerous barriers to care including “the stigma associated with mental illness, lack of knowledge about services, difficulty accessing services, conflicting personal obligations, individual belief that they did not have a problem, and fear of treatment.” Group

members also demonstrated a lack of knowledge about WTC-related illnesses and were concerned about receiving medical services from the EHC instead of their usual PCPs.

To address the enrollees' concerns about the stigma of mental health, the Registry provided special training in motivational interviewing to staff members who refer enrollees to WTCHP health services. The training "allows staff to better educate enrollees on the possible connection between their symptoms and the 9/11 disaster and minimize feelings of apprehension about the connection, address barriers to care, and ultimately provide optimal linkages to 9/11 specialty care. Moreover, to address the stigma surrounding mental health, staff members are trained to normalize enrollees' feelings about their post-9/11 mental health symptoms and health care." The Registry is also developing processes to engage enrollees' PCPs in the referral process to specialty WTCHP medical services.

The Registry also has provided new evidence of health risks to the WTC-exposed population from conditions that are not yet recognized as WTC-related. In a series of studies, increased risks for heart and cerebrovascular disease has been noted in Registry enrollees. High 9/11-related exposure was associated with increased mortality from heart disease among area residents and workers.⁶⁹ Dust cloud exposure, injury on 9/11, and event-related PTSD were associated with an elevated risk for self-reported physician-diagnosed heart disease 2 to 6 years after the disaster among Registry enrollees.⁷⁰ In a recent study based on data from New York State's SPARCS hospitalization discharge reporting system, a high overall level of WTC rescue- and recovery-related exposure was associated with an elevated heart disease hospitalization risk in men but not in women. Women, but not men, with PTSD at enrollment were found to have an elevated risk for hospitalization for heart disease, whereas men with PTSD at enrollment were found to have an elevated rate of hospitalizations for cerebrovascular disease.⁷¹

The WTCHP program administrator has not yet identified heart disease or cerebrovascular disease as WTC-related conditions for which care may be provided under the Zadroga Act. Coverage of an illness under the Act greatly eases the financial burdens of those afflicted with it. These current findings should provide an impetus for further research on cardiovascular disease in the WTCHP population and its relationship to exposure to WTC toxins.

DISCUSSION

This review identifies several elements that have had a critical impact on the evolution of the WTC response and, directly or indirectly, the health of the WTC-exposed population.

1. Developing trust: The success of a long-term monitoring program is largely dependent on winning the trust of the exposed community, an intangible but essential foundation for longer-term engagement. The 14-year experience following the 9/11 disaster has demonstrated the effects of both lack of transparency, particularly with regard to environmental exposures, and of increased transparency, including establishment of a STAC.

A very informative paper about the public health response to the 2005 Graniteville, South Carolina chlorine spill described the efforts of public health agencies to win the trust of the exposed population. Regular communication, transparency, and responsiveness were key factors in building what became a collaborative effort between the agencies and the community. As this partnership evolved, the agencies engaged stakeholders in the community so that ongoing public health research might continue with community support over the long term. The result has been the funding of a longitudinal cohort study and other grants that have direct benefit to the Graniteville community.⁷²

In the paper on Graniteville, the authors described a process that is familiar to us, that of regular communication with the victims of the disaster and the most painstaking transparency in that communication to establish trust. Pre-existing relationships between medical institutions and groups of responders aided the development of trust, as did outreach to workers. But the inadequate assistance offered post-9/11 for the cleanup of Lower Manhattan residential buildings, offices, and schools, and official denials of hazardous environmental impact, resulted in a justified sense of grievance in the survivor community. The subsequent delay in opening the EHC for the community magnified this disillusionment, discouraged its utilization, and damaged the relationship between the responsible agencies and the community.
2. Clinical expertise and data: This long-term perspective also affords us the opportunity to appreciate just how important the observations of trained occupational and pulmonary medicine specialists were in recognizing the threat of the WTC exposure; and how critical the pre-existing routine spirometric evaluations that had been provided to first responders were to quantitating that threat.
3. Site safety and worker training: The absence of simple site safety measures such as a roster, site control excluding untrained personnel, and site-specific hazard training had a lasting and terrible effect on the health of some untrained responders. Some of these responders remain unknown, unmonitored, and untreated to this day. Current news stories emphasize the importance of these factors to the management of ongoing disasters. For example, the vital role of trained workers in maintaining public confidence in an ongoing cleanup is illustrated by reports of public

- concern about high personnel turnover at Fukushima's damaged reactor, with increasingly inexperienced workers being charged to undertake critical environmental cleanup functions.⁷³
4. Assessment of acute and chronic exposure: The 14-year perspective underscores the importance of acute and chronic exposure measurement in explaining WTC-related illness, and of surrogate measures, such as being caught in the dust cloud as an expression of acute exposure and the depth of the dust layer in residences for chronic exposure. This perspective also highlights gaps in disaster response and monitoring, in particular, the lack of a vigorous governmental effort to guide clean up in the Lower Manhattan community. Limiting the survivor program to those who are symptomatic and needing treatment for 9/11-related illness, unlike responders who receive monitoring based on exposure only, resulted in major limitations to clinical surveillance of the overall exposed survivor population. This failure stands in striking contrast to the efforts of authorities in other disasters to understand population exposure and risk. For example, within months of the Fukushima nuclear accident, the Japanese government mailed surveys designed to gauge radiation exposure to >2 million residents of the Fukushima Prefecture.⁷⁴ And although it is true that certain reactions by government authorities to community contamination may make matters worse—and other disasters, such as Fukushima, have illustrated the very real dangers of relocating a vulnerable community's population in response to an environmental hazard⁷⁵—the failure to design, mandate, and carry out a relatively simple cleanup for toxic dust in Lower Manhattan placed this entire community at increased risk for exposure to known toxins.
 5. Attention to vulnerable populations: The response to the WTC disaster demonstrates how even in relatively high-resource countries, vulnerable populations can be overlooked in pre-emptive disaster responses. Specifically, the short- and longer-term effects of the terrorist attack and environmental disaster on children with direct exposure (lived or went to school in the area) and those with indirect exposure (parents with direct exposure) received limited attention during the decade following the disaster. This is an extremely vulnerable population that has only recently received funding for study, with the incumbent limitations of delays in identification, recall bias, and the confounders that will arise as children grow to adolescents and young adults.
 6. Mental and physical health integration: There has been growing appreciation and documentation of the bidirectional effects of physical and mental health after 9/11, with high levels of comorbidity among those affected by aerodigestive disorders and cancer as well as PTSD, anxiety, and depressive disorders. There

remains much to learn about what kinds of therapeutic interventions will optimize outcomes for such a heterogeneous population, and this remains an underdeveloped area of investigation.

7. Transparency and responsiveness: As evidenced by the development of a STAC, there is a framework for encouraging transparency, openness, and responsiveness to the concerns of the exposed population. The very public nature of the cancer review process, and the clarity with which it addressed its goals helped reassure responders and survivors of its basic fairness. It stands in very stark contrast to the earlier “nondecision” and lack of guidance by federal and local authorities regarding the cleanup of residences and businesses in the downtown community.

Like the Graniteville community, we continue to hope and strive for the clear communications and transparent decision making that have been key to building and maintaining responder, survivor, and public confidence in the response to the WTC disaster.

CONCLUSIONS

We have identified key elements of the WTC response that have affected the health of the exposed population and ongoing population monitoring and treatment. Critical components of this response influencing, and being influenced by, its dynamic multifaceted structure include the role of specialists with experience in occupational and pulmonary medicine, trained responders with pre-existing health data, basic site safety measures, physical and mental health evaluation, exposure evaluation and control, and vulnerable subpopulations. The failure of responsible government agencies to address widespread contamination exposed WTC community residents to unnecessary health risks. Responders also were put at unnecessary risk by the failure of responsible agencies to enact and coordinate strict health and safety policies during recovery operations. The value of trust and transparency between the exposed populations and the public health authority in environmental disasters is well established. Operationalizing these ideals amidst the initial chaos and longer-term bureaucratic challenges that are an integral part of any disaster remains a daunting but essential mandate.

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