Epidemiologic Research on Man-made Disasters: Strategies and Implications of Cohort Definition for World Trade Center Worker and Volunteer Surveillance Program

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ABSTRACT

Studies of long-term health consequences of disasters face unique methodologic challenges. The authors focused on studies of the health of cleanup and recovery workers, who are often poorly enumerated at the outset and difficult to follow over time. Comparison of the experience at the World Trade Center disaster with 4 past incidents of chemical and radiation releases at Seveso, Italy; Bhopal, India; Chernobyl, Ukraine; and Three Mile Island, USA, provided useful contrasts. Each event had methodologic advantages and disadvantages that depended on the nature of the disaster and the availability of records on area residents, and the emergency-response and cleanup protocol. The World Trade Center Worker Monitoring Program has well-defined eligibility criteria but lacks information on the universe of eligible workers to characterize response proportions or the potential for distortion of reported health effects. Nonparticipation may result from lack of interest, lack of awareness of the program, availability of another source of medical care, medical conditions precluding participation, inability to take time off from work, moving out of the area, death, or shift from initially ineligible to eligible status. Some of these considerations suggest selective participation by the sickest individuals, whereas others favor participation by the healthiest. The greatest concern with the validity of inferences regarding elevated health risks relative to external populations is the potential for selective enrollment among those who are affected. If there were a large pool of nonparticipating workers and those who suffered ill health were most motivated to enroll, the rates of disease among participants would be substantially higher than among all those eligible for the program. Future disaster follow-up studies would benefit substantially by having access to accurate estimates of the number of workers and information on the individuals who contributed to the cleanup and recovery effort. ***Mt Sinai J Med 75:77–87, 2008.*** © *2008 Mount Sinai School of Medicine*

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Epidemiologic investigations of the consequences of unexpected disasters, whether man-made or natural, are inherently limited by lack of anticipation and preparation for the research that follows. Although there are many studies of the health of those potentially affected by disasters, the unanticipated nature of the event makes it more difficult to carefully define the population of interest, measure exposure, and prepare for longitudinal health studies that follow. Studies of man-made and natural disasters, therefore, deviate from the ideal approach to study planning: specification of hypotheses in advance,

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identification of a suitable population for addressing the research question, accurate measurement of exposure, enrollment of participants to ensure comprehensive identification and a high rate of participation, administration of informed consent to participate in the study, and ensuring the ability to track participants' health status over time.

In the immediate aftermath of a disaster, long-term health concerns are of less concern than immediate threats to health and the environment. Gathering data that are needed to enumerate potentially exposed individuals is typically done post hoc by reconstructing information based on records of residences or jobs, anecdotal reports, or self-identification. Exposure measurements while the disaster is unfolding are rarely available, requiring reliance on historical exposure reconstruction through environmental modeling or individual reports of exposure. As concern shifts from acute to delayed effects of disaster, there is a need for accurate and comprehensive follow-up of exposed cohorts.

Accurately defining populations at risk of long-term health effects from the attacks on the World Trade Center (WTC) has been problematic from the outset, particularly with regard to those who assisted in the recovery efforts. There are several features of the disaster that pose challenges to accurately describing long-term health consequences of those experiences: the spectrum of exposure, including both environmental chemicals and psychological trauma; the location of the WTC in a densely populated residential and work area; and the many sources of workers who responded to help immediately and in the weeks and months that followed the attack.

In this discussion, we focus on the men and women who responded to the disaster and provided assistance after the WTC attacks, specifically on implications of cohort definition and recruitment for studies of exposure and health outcomes. First, we briefly review strategies employed to define exposed populations in past disasters, focusing on those performing rescue, recovery, restoration of services, and cleanup. Then, we consider, in some detail, the ideal and operational cohort definitions used in ongoing follow-up studies of WTC responders, considering the implications for inferences on exposure and health outcomes.

SUMMARY OF HEALTH RESEARCH ON PREVIOUS DISASTERS

Although each disaster situation is unique, prior disaster studies offer useful perspectives for evaluating the WTC worker health studies. Table 1 summarizes the key features of 4 broadly analogous disasters in which ionizing radiation or chemicals were released and affected large populations.[1–18] Like Bhopal, India, the WTC attack occurred in a highly urban setting, proximal to a large population of residents, students, and workers. As the US, is a more developed country, study of events here offers some advantages over studies of events in India and Ukraine such as an emergency response infrastructure and some records for enumerating residents and workers.

The environmental health concerns from visible dust exposure in the WTC attacks lend themselves to self-report in contrast to the ionizing radiation exposure at Chernobyl and Three Mile Island. However, ionizing radiation constitutes a specific agent with well-understood health effects, whereas the WTC exposures were an extremely complex mixture of agents contained in the dust from the collapsed buildings along with products of combustion. In addition, ionizing radiation is routinely monitored at sites of nuclear power plants, generating some baseline data and clues to an evolving disaster, whereas there was no corresponding information available for the WTC disaster.

The WTC attacks were immediately obvious, in contrast to the dioxin contamination at Seveso, which was not recognized for more than a week after it occurred. The intentional nature of the attack on the WTC tended to focus initial attention more on national security than on environmental health. Given that concern with security associated with the attacks on the WTC, the priority given to long-term health consequences was perhaps lower than in any of the other situations characterized in Table 1. In other disasters, the shift was from acute to chronic health effects, whereas after the WTC attacks, the shift was from acute health effects to the military and political response and then, after some delay, to chronic health concerns. National security concerns did not diminish in the aftermath of the disaster, reducing the attention given to the health of cleanup workers.

IDENTIFICATION OF RESPONDERS IN PREVIOUS DISASTER RESEARCH

Residents located near a disaster area can often be enumerated, even retrospectively, on the basis of existing records or by obtaining household rosters. Employees are typically amenable to identification

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Table 1. *Summary of Disaster Experience and Epidemiologic Follow-up Studies for Long-term Health Effects: Seveso, Chernobyl, Three Mile Island, and Bhopal.*

Geographic location	Date of event	Primary exposure of concern	Residential population	Affected employed population	Emergency responder population	Cleanup worker population	Limitations and strengths
Seveso, Italy (Province of Milan)	July 10th, 1976	2,3,7,8–Tetrachloro-dibenzo-*ρ*-dioxin (TCDD) (dioxin)	Population: Highly documented. ~28,000 residents (1). 733 in most highly exposed residential area, Zone A (1,3). Method of determination: Based on mapping of TCDD soil concentrations (2) and records of residence. Medical/public health response: Surveillance measures were undertaken for 220,000 residents (1,3). Systematic medical testing and surveillance for randomly selected cohorts; 17,000 residents from Zones A, B and R received systematic medical testing through 1984 (1,5). All school children (32,200) received skin examinations (1,4). Health outcomes tracked through records of health care providers and vital statistics.	Population: Highly documented. Industrie Chihiche Meda Societa (ICMESA) chemical plant workers Method of determination: Chemical plant documents. Medical/Public health response: Workers were evaluated in specialized health studies as one of the subgroups in a randomly selected cohort.	Population: Not documented. Local emergency response Medical/public health response: Emergency responders did not receive special focus in heath studies.	Population: Highly documented. Decontamination workers. Method of determination: Detailed records of "cleanup" employees including medical entrance exam. Medical/Public health response: Workers were examined before entrance into Zone A and again after 9 mo of decontamination work (4) to ensure limited exposure.	Limitations: Presence of TCDD[a] was unknown until 9–10 days after the incident (2–4). Strengths: Residence registrars made identification of residents in severely affected areas accurate and nearly complete.

(*continued overleaf*)

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Table 1. *(Continued).*

Geographic location	Date of event	Primary exposure of concern	Residential population	Affected employed population	Emergency responder population	Cleanup worker population	Limitations and strengths
Three Mile Island Nuclear Power Plant (10 miles away from Harrisburg, PA)	March 28th, 1978	Ionizing radiation (total release of ~2.5–10 million curies, radioactivity)	Population: Highly documented. ~35,900 residents living within a 5-mile radius of the Three Mile Island (TMI) Nuclear Plant (11). Method of Determination: Based on records of residence. Medical/Public health response: TMI Population Registry. Door-to-door canvassing of 5-mile radius around TMI to administer standardized questionnaires (11).	Population: Highly documented. 533 TMI Nuclear Plant workers (12). Method of determination: Based on plant employment records. Medical/Public health response: Permanent TMI Employees as of March 1st, 1979 were surveyed by telephone interview (12).	Population: None. No emergency response—no explosion or fire occurred.	Population: Highly documented. >1,000 (13). Method of determination: detailed records of "cleanup" employees. Medical/Public health response: Worker exposure monitored very closely. As of 1990 average worker dose 62.17 person–Sieverts (Sv) (14)	Strengths: Affected population geographically contained. Accurate and up-to-date residence information. Complete employee roster for the TMI Plant. Able to utilize effective state and national organizations with experience in registering communities. Also had sufficient resources for follow-up and data processing.
Bhopal, India (population of 800,000–1,000,000) (15,16)	December 2nd to 3rd, 1984	Methyl isocyanate (MIC) (27–40 tons (16–18)) and decomposition by-product hydrogen cyanide.	Population: Poorly documented. 520,000 exposed residents; 200,000 residents lived in high exposure areas (15,16). Method of determination: Areas of exposure defined as severe, moderate and mild according to mortality of both humans and animals (15).	Population: Not documented. Known to be Night Union Carbide Plant Workers.	Population: Not documented.	Population: No substantial cleanup effort and no employee roster. Medical/Public health response: No follow-up.	Limitations: Poorly defined population. Exact number of dead is unknown because official records only documented those who died in hospitals and bodies were burned soon after.

			Medical/public health response: Bhopal Gas Disaster Research Center in 1985, registered ~80,000 residents from severely, moderately and mildly affected areas as well as ~15,000 from unaffected Bhopal areas (15–17). Population Based Cancer Registry in Bhopal in 1986.				
Chernobyl town and neighboring town, Pripyat.	April 26th to 27th, 1986	Ionizing radiation (mostly in Belarus, Russian Federation, and Ukraine. Dispersed across Europe)	Population: Partially documented. ~340,000 evacuated from area (6,7) ~120,000–135,000 residents living within 30-km radius of the Power Plant (6,8) ~2,326,000 exposed residents, evacuees, re-settlers and children born to exposed parents living in the exposed areas of Russia, Ukraine and Belarus. Method of determination: Based on proximity to disaster site, dates of residence, self report, etc. Medical/public health response: 50,000 radiological examinations on the evacuees, residents and workers.	Population: Partially documented. Chernobyl Nuclear Power Plant workers. Method of determination: ARS diagnosis in aftermath of disaster. Medical/public health response: Only those Nuclear Plant workers diagnosed with ARS received specialized follow-up care and had their medical outcomes tracked.	Population: Partially documented. ~600 emergency personnel participated in fire department and helicopter response (7). Method of determination: ARS diagnosis in aftermath of disaster. Employment records. Medical/public health response: All surviving individuals of the initial 237 suspected cases of acute radiation sickness have undergone long-term monitoring (7,9).	Population: Partially documented. ~300,000–600,000 (7,8) Method of determination: 537,000 liquidators registered in the Chernobyl registries of Russia, Ukraine and Belarus (9). ~600,000 Liquidators were issued certificates of service onsite. Once registered, participants were required to undergo annual exams (7,10). Russia, Belarus and Ukraine all have established clinics for the monitoring of liquidators as well as institutions dedicated to providing them with specialized medical care and rehabilitation (9).	Limitations: No complete roster of Chernobyl liquidators. Reliant on individual's account of duties and location in estimating radiation dosage. Large incentive to forge liquidator status as it was linked to many social and medical benefits. Liquidators were not geographically contained. Strengths: Great incentive for liquidators to enroll in national registries so as to gain access to benefits.

[a] 2,3,7,8 - Tetrachlorodibenzo-ρ-dioxin

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and enumeration through payroll lists or time sheets for employees who were present at work on a specific day. In sharp contrast, responders are comprised of an ad hoc assembly of individuals brought in on an emergency basis, often in an unplanned, poorly documented manner. In the initial phase of response, help is often sought from wherever it can be found, including designated emergency response workers, local residents and workers, and volunteers seeking to be of assistance. They are identified solely by their activity of participation in the cleanup operation, with no counterpart to residential or employment records to reconstruct the roster or source population from which they came.

Because the Seveso dioxin contamination episode was not identified until the chemical release was over and health risks were known to be present,[2–4] cleanup workers were engaged in a coordinated, well-documented manner; medical examinations were made before beginning work and again after 9 months of effort.[4] Similarly, in the Three Mile Island nuclear accident, around 1000 cleanup workers were engaged and individually monitored for ionizing radiation exposure by using personal dosimetry.[13,14] In Bhopal, there has been little documentation of response activities or the number or source of workers involved.

The Chernobyl nuclear disaster offers the most relevant analogy to the WTC worker health studies. The accident at Chernobyl in 1986 engaged emergency response workers during the days after the accident, with levels of ionizing radiation producing acute radiation sickness symptoms in approximately 237 patients, of which 145 were diagnosed with acute radiation syndrome (ARS).[7] Later, liquidators were recruited from Belarus, Russia, and Ukraine to come to the accident site and decontaminate the facility. Around a half million of these liquidators were engaged to decommission the plant, drawing on populations of 3 different countries.[9] (Table 1). The scale of the operation resulted in a system of clinics and health data systems focused on such workers, and a sizable volume of sophisticated epidemiologic studies have resulted. The systematic approach to hiring and monitoring these workers supports epidemiologic follow-up studies. The WTC rescue and recovery workers were not hired or documented in a comparable manner.

WORLD TRADE CENTER WORKER MONITORING PROGRAM: ELIGIBILITY AND ENROLLMENT

The ongoing World Trade Center Worker and Volunteer Medical Screening and Medical Monitoring Program, referred to here as the WTC Worker Monitoring Program, was established in July 2002 to provide comprehensive medical monitoring examinations for workers and volunteers who were engaged in rescue, recovery, restoration of services, and cleanup after the attacks on the WTC. A separate monitoring program was established by the Fire Department of New York for New York City firefighter responders. A federally funded treatment program for both cohorts was added in November 2006.

The WTC Worker Monitoring Program includes a clear operational definition of eligibility based on an exposure matrix of tasks performed combined with time and duration of work at the site. Initially, eligibility was narrowly defined to include only those individuals who had worked within the geographic area of "the pile" and its perimeter. Time requirements consisted of working 24 hours during the first 3 days following the attacks or a total of 10 days at the site in the month of September 2001.

Over time, as clinic capacity increased, eligibility criteria underwent multiple expansions. The task requirement stayed the same, with workers or volunteers required to have performed rescue, recovery, cleanup, or restoration of essential services. The geographic scope expanded, however, to include Manhattan below Canal Street, the barges, the Staten Island landfill, and several other locations where work did not necessarily occur within the stated geographic boundaries (eg, vehicle maintenance on WTC-dust-contaminated trucks that were transported to garages in Brooklyn and Queens). The time requirements were expanded to include several alternatives: 4 hours between September 11 and 15, 2001; 24 hours between September 11 and 30, 2001; or 80 hours from September 11 through December 30, 2001, which is the date that the fires at the site finally ended. Ascertainment of eligibility is conducted by staff at a telephone bank and is based on self-reported exposures.

Eligibility criteria for enrollment also changed in response to availability of alternate programs for other categories of workers. For example, federal and New York state workers were initially *not* eligible for the WTC Worker Monitoring Program, but as monies for programs for these workers ran out, the eligibility criteria were changed to allow those individuals to enroll.

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Several groups were eligible for inclusion in the program when they met special requirements. Port Authority Trans–Hudson train (PATH) workers were eligible if they met separate time and location requirements, working in the PATH tunnels for at least 24 hours during the period from February to July of 2002. This exception was made because cleanup of the PATH tunnels, which were heavily damaged and contaminated by a significant amount of dust and debris, did not begin until February 2002. Employees of the Office of the Chief Medical Examiner were eligible despite the amount of time worked or the location of their work.

Given the nature of cleanup operations and application of eligibility criteria based on engaging in *activities* rather than satisfying specific *administrative criteria* (eg, belonging to specific worker groups), there is no roster of those individuals eligible to participate. That is, there is no listing of all individuals who were engaged in specific activities at locations and in time periods of interest that would qualify them for participation in the WTC Worker Monitoring Program. We have a roster of individuals deemed eligible by the telephone bank who chose not to make at least 1 visit to the clinical center, and a roster of those who had at least 1 visit to the clinical center. We have essentially no information on the number or identity of those who did not contact the telephone bank.

Extensive efforts were made to make diverse, eligible individuals aware of the program through newsletters and mailings and widespread media coverage, especially in the New York area. Telephone calls have been received from 29,591 presumably eligible individuals based on the eligibility criteria in effect at the time of their call or who were initially not eligible but became eligible as the criteria were expanded. It is inevitable, of course, that some of those who are eligible have not participated even at the level of a telephone call, which raises concern about their potential need for expert clinical care. However, our focus is on the potential for incomplete coverage of those eligible to affect research on the relation between WTC exposures and health outcomes. The loss of otherwise eligible participants, even if truly random, incurs some loss of statistical power because of the smaller number of responders available to study. Moreover, there is a real possibility for such losses to be nonrandom with regard to the exposures and outcomes of interest. That is, when we evaluate the relation between WTC exposures and long-term health consequences by studying the individuals who participated in the WTC Worker Monitoring Program, we are susceptible to drawing different inferences than we would have if all those who were eligible had participated in the program.

Initial estimates of the number of workers eligible for the program by Mount Sinai staff was approximately 40,000, subject to some uncertainty. This number was derived from estimates given by several major groups involved in the recovery effort, including the American Red Cross and major labor unions. The estimate excluded employees of the Fire Department of New York, which had their own program, and both federal employees and New York State employees who were not eligible for the Mount Sinai program because they were able to participate in employer-coordinated programs. The New York City Department of Health and Mental Hygiene, which is conducting their own health assessments of the population exposed to the World Trade Center disaster through the World Trade Center Health Registry,[19,20] has published estimates that 91,469 workers and volunteers would be eligible for their registry. However, eligibility criteria for their registry were notably different from the World Trade Center Worker Monitoring Program: 1) The time requirement for participation in the World Trade Center Registry was "1 shift" between September 11, 2001, through June 30, 2002, which is far less restrictive than the time period required for participation in the World Trade Center Worker Monitoring Program; 2) Their estimate includes 26,480 volunteers, among whom some unknown fraction would not meet the eligibility criteria for our population; 3) Their estimate includes 8897 workers from State Agencies as well as 5122 Federal employees who were initially not eligible for participation but who were included later; and 4) They include 13,500 firefighters who have their own program and were, thus, not part of our monitoring. Some (but not all) of these considerations could be addressed to reconcile the various estimates and to generate information on the approximate response proportion among those eligible for the World Trade Center Worker Monitoring Program. In the absence of clear documentation, the number of workers meeting specific eligibility criteria is subject to substantial uncertainty. With nearly 30,000 eligible individuals having made at least telephone contact with the World Trade Center Worker Monitoring Program, we estimate that the response proportion is currently between 50% and 70% and increasing steadily as new participants continue to call.

Given the broad eligibility criteria for participation in the WTC Worker Monitoring Program based on the location, time, and duration of activities, the cohort includes workers with wide variation in type and magnitude of exposure. Some responders

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experienced intense, but brief, exposure during the first days after the disaster with intense exposure to contaminated air and unstable physical working conditions, as well as psychological trauma resulting from recovery of body parts and uncertainty surrounding what was happening. Workers who started working at a later date, but worked for a longer time, had a different exposure experience both physically and psychologically.

IMPLICATIONS OF INCOMPLETE COVERAGE

To empirically describe the nature of incomplete enrollment and its implications for assessing the impact of WTC exposures on worker health, we would need data on those persons who were eligible but did not enroll. As indicated above, this information is not available, leaving us only with informed speculation based on the general experience in other studies and integrated with the specific features of the WTC Worker Monitoring Program.

The reasons that some members of the universe of eligible workers have not participated are likely to be diverse. We consider a spectrum of possible pathways by which this could have occurred and the implications of each with regard to both exposure and health status. To the extent that such losses are nonrandom with regard to exposure, inferences of possible health risk may be exaggerated or understated. If more highly exposed workers participated in the monitoring program and suffered increased health risks as a result of their elevated exposure, we would overstate health risks if their experience is assumed to apply to all those eligible for the WTC Worker Monitoring Program and, conversely, if the less exposed workers participated preferentially. To the extent that participation is related to health status, we will overstate the effect of their experience if the sickest workers are most likely to participate and understate the effect of their experience if the healthiest workers are preferentially enrolled.

However, neither of those scenarios necessarily results in a distortion of the measured relation between exposure and disease.[21] The opportunity to compare health outcomes among participants with greater and lesser degrees of exposure is advantageous in that the unknown losses of eligibles are less likely to be problematic for comparisons among participants than for comparison of participants to external populations. Only a situation in which nonparticipation results in selective inclusion (or exclusion) *jointly by exposure and health status* will distortion of exposure–response result. If those workers who are least exposed *and* healthiest fail to participate, or those who are most exposed *and* sickest fail to participate, we will underestimate the magnitude of exposure impact on health. Similarly, if those who are least exposed *and* sickest fail to participate, or those who are most exposed *and* healthiest fail to participate, we will overestimate the magnitude of exposure's impact on health. Issues of joint determination of participation based on exposure and health outcomes are more complex and less plausible than an influence of exposure or health status alone.

POSSIBLE REASONS FOR INCOMPLETE COVERAGE

No Interest in the Program

As in most voluntary activities, a proportion of potential participants will choose, often with relatively modest deliberation, to decline to enroll simply for lack of time or interest. Although the potential health consequences of WTC involvement are very significant to many of those exposed, a subset may either prefer not to dwell on their past experience or find medical-monitoring activity irrelevant in their day-to-day lives because of the absence of known health problems. Despite the magnitude of the event, some fraction of workers, likely among the healthiest, would assign medical monitoring to a low priority.

No Awareness of Program or Eligibility

Given the diversity of groups involved in the cleanup effort, it remains quite possible that some of the individuals who participated and would qualify for the WTC Worker Monitoring Program are simply unaware of the program's existence or their eligibility to obtain clinical care through the program. Those most likely not to be reached are those who are no longer affiliated with their former organization (eg, union, employer) and not attending to media. Both leaving employment and social isolation would likely be associated with worse health status, on average. Those with the most immediate and intense exposure in the cleanup effort are more likely to be aware of their eligibility than those with delayed or less intense exposure, eg, on the waste pile rather than at the building site.

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Medical Care Outside of the Program

Those individuals who have ongoing medical care and are pleased with their current health care provider may believe that there is no benefit from clinical services provided by the WTC Worker Monitoring Program. Those who have private medical care (and are, thus, of greater economic means) may be less likely to perceive benefit from the program. Alternatively, those who are receiving ongoing care for a serious illness may be reluctant to obtain additional medical services. Greater economic means would be predictive of more favorable health status, whereas ongoing care for a chronic illness would be indicative of less favorable health status.

Illness

Workers who are hospitalized or severely debilitated may find it unfeasible to come to the clinic site for logistical reasons. Although efforts have been made to accommodate all who are interested in being seen, doing so does require a minimum degree of mobility and function. Obviously, those who are physically unable to come to the clinic sites would have much worse health status than those who are able to do so.

Time Off

Given the need to travel to the clinic and be absent from work during normal work hours, those whose jobs do not facilitate clinic participation would be less likely to do so. Among the spectrum of responders, this would encourage selective enrollment of those relatively few whose employers provided paid time off for examinations. Most have had to use nonwork time to take advantage of clinic services.

Moved

While there is a national network available to those individuals who are eligible but do not live in WTC area, this would be less well known and perhaps seen as less salient among those outside the area. Those residing outside the New York/New Jersey metropolitan area tend to fall into 4 categories: 1) urban search and rescue teams and other groups of responders who had lived outside the area at the time of the disaster; 2) those who retired at the usual age then moved away; 3) those who retired early or were disabled because of WTC-related illnesses and who relocated for economic and/or health reasons; and 4) those who relocated for economic opportunity or other reasons. Obviously, these very different reasons for residing outside the area have different implications for health, with illness-related retirement, of course, being associated with poor health status and moving for economic reasons being a more favorable sign with regard to health.

Deceased

The numbers of individuals who have died would likely be small, whether related or unrelated to exposures received in the WTC cleanup and recovery activities, given the selectively healthy population of volunteers at the site and the relatively brief period of time since September 11, 2001. Such losses would deplete the cohort of less healthy individuals compared with those who are still living.

Initially Ineligible but Became Eligible Through Changes in Criteria

Those workers who were initially ineligible because of duration or location of work or for administrative reasons because their employer may be less likely to have learned of their eligibility compared with those who were aware at the beginning.

IMPLICATIONS OF INCOMPLETE ENROLLMENT ON INFERENCES REGARDING EXPOSURE AND HEALTH OUTCOMES

There are multiple plausible reasons that eligible workers may not enroll in the WTC Worker Monitoring Program, as enumerated above. The greater the proportion of eligibles who enrolled, the lower the risk of selection bias resulting in distortion of disease rates and measures of association between exposure and disease. Acknowledging that participation is less than complete because of unknown (and probably unknowable) extent, the next concern is whether those who have enrolled are selectively healthy or ill compared with those who did not enroll. There is much interest in comparing the rates of illness among WTC Worker Monitoring Program participants with the general population, as determined through disease registries, health surveys, and other means. Where rates of disease are notably higher in WTC responders, the inference is that their work experience is likely to have contributed to that elevation in risk. To the extent that the rate of disease among participants is markedly different from the rate of disease that would have been observed among all those who actually responded (eligibles), inferences will be inaccurate.

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Although we are lacking data to directly address the magnitude or direction of distortion comparing those enrolled with the entirety of those who were eligible, there is a reasonable basis for speculating on tendencies for participants to be selectively healthy or unhealthy. In general, the presence of illness makes any health or medical activity (clinical or research) more salient and, thus, more worthy of investing one's time. Other considerations being equal, those who have health concerns, symptoms, or illnesses are more likely to take advantage of the WTC Worker Monitoring program than those who are in good health for whom health is simply not a pressing concern. The greatest risk of having spuriously elevated rates of disease among WTC Worker Monitoring Program participants is the potential for enrollees to represent the sickest among a much larger pool of eligible workers. The magnitude of this distortion depends on the proportion of eligibles who participated, the magnitude of the tendency for the least healthy to be most likely to enroll, and the impact of compensating tendencies in the other direction, favoring enrollment by the healthiest individuals.

There are several reasons to expect competing tendencies that tend toward selective participation by the healthiest responders. Lack of awareness of the program and inability to take time from work would result in nonparticipation, and both are likely to be associated with lower health status, on average. Obviously, loss of those who are too severely ill to participate or those who are deceased, and those who already have medical care because of serious illness and, thus, do not participate would result in a more favorable health profile among participants. The relative magnitude of these competing tendencies is unknown, and, thus, the net impact of nonresponse on estimated disease rates cannot be estimated with certainty.

Beyond the interest in characterizing the health experience of workers in aggregate, we are interested in gradients in risk of disease associated with *level* of exposure among participants in the monitoring program. That is, we will compare health outcomes among those with greater exposure to those with lesser exposure. In such comparisons, the potential for erroneous inference is much less because all workers (both those with higher and lower exposure) are subject to selective influences for participation. To the extent that meaningful gradients in exposure can be identified among the participants, requiring separation of those with little or no exposure from those with more substantial exposure, the strength of inferences will be markedly enhanced. For dose–response gradients to be influenced by selective participation, there would have to be more complex patterns of response jointly by both exposure and disease status.

In the face of these competing influences of unknown magnitude, sensitivity analyses would be of value to help characterize the certainty of findings linking WTC exposures and disease. Such an approach would entail various assumptions about the likely magnitude of each of the many pathways of loss of eligible participants and incorporating those probabilities into the distribution of possible values for the measure of association.[22] Limited data on each of the mechanisms of nonparticipation would require speculation and generate a wide range of possibilities, but they would help to bound the potential biases. A formal sensitivity analysis is beyond the scope of this more general discussion of the concerns but warranted as a means of evaluating the validity of specific findings as they emerge.

LESSONS FOR DISASTER EPIDEMIOLOGY

Although evaluation of health consequences of disasters must, by definition, be unplanned because of the unpredictable nature of the precipitating event, some suggestions can be offered for improving inferences regarding long-term health effects without distracting from the need for immediate action. Key to all future studies is the need for some information on the size of the workforce that participated, ideally including their demographic profile or, even more optimally, their registration for future follow-up. Even if such information is unattainable in the immediate hours and days after the event, in the weeks that follow, an increasingly organized and fully documented approach should become more feasible.

The evolution from acute health concerns to chronic health concerns can be anticipated. Provision of services for acute, physical trauma inevitably extends to long-term physical and mental health concerns. Perhaps some of the long-term consequences could be averted by more complete follow-up and care from the beginning. More systematic enrollment and monitoring would not only provide a firmer basis for inferences regarding health risks but would also result in better clinical care. Such plans should be developed as part of a comprehensive disaster management strategy, building upon and not detracting in any way from the acute health concerns associated with such disasters.

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