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GRACE: Public Health Recovery Methods following an Environmental Disaster

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Abstract

Different approaches are necessary when Community Based Participatory Research (CBPR) of environmental illness is initiated after an environmental disaster within a community. Often such events are viewed as golden scientific opportunities to do epidemiological studies. However, we believe that in such circumstances, community engagement and empowerment needs to be integrated into the public health service efforts in order for both those and any science to be successful, with special care being taken to address the immediate health needs of the community first rather than the pressing needs to answer important scientific questions. We will demonstrate how we have simultaneously provided valuable public health service, embedded generalizable scientific knowledge, and built a successful foundation for supplemental CBPR through our on-going recovery work after the chlorine gas disaster in Graniteville, South Carolina.

Keywords

disaster; epidemiology; environment; chlorine; community based participatory research; ethics; public health; Graniteville

Introduction

Chemical exposure events resulting in environmental health disasters within communities are not unprecedented, nor are community based approaches to recover from them. If well studied, such events can provide scientifically robust information on the human health effects of that specific chemical[1]. However, performing a scientific study in the wake of a disaster can have additional limitations[2].

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Though they have not been thoroughly discussed in the context of Community Based Participatory Research (CBPR), the Hiroshima and Nagasaki survivor studies actually were some of the first CBPR studies ever performed[3-12]. Many epidemiologists may have forgotten, also, that the research on these cohorts did not actually begin until after years of public health service, capacity building, community engagement/co-operation, and community empowerment[7, 13, 14]. United States scientists co-operated with Japanese scientists equitably, and engaged many city and national groups in the design, implementation, and performance of the public health services and later research with the explicit goal of helping the casualties to recover through methods that were sensitive to the Japanese culture[13]. The temporal lag between the events and eventual initiation of research allowed the communities to begin to recover. Also, during the period prior to being studied the affected communities were provided many public health and relief services which built their trust in the United States and their researchers who eventually were able to engage those communities in both the longest and largest prospective cohort study ever performed following a single environmental exposure event. The communities were engaged in how the studies would be performed, local scientists and clinicians performed the clinical assessments and services required for the communities, and all correspondence with the participants was orchestrated through local partners. The Hiroshima and Nagasaki studies were ahead of their time, and served as ideal models to guide our team in our recovery and epidemiology efforts following a much smaller environmental health disaster.

Other disasters since Hiroshima and Nagasaki, too, have used CBPR related principals embedded within both the public health services provided and any resulting research that was pursued. The most recent example is the recovery efforts following the World Trade Center Collapse[15]. But the most complete work currently in the literature is from the recovery of the Mt. St. Helens volcanic eruption[16-29]. In both the 9/11 and Mt. St. Helens disasters human subjects research studies were initiated only in response to the desire for the local communities to have a better understanding of the uncertainties of their health after their exposures during the disaster. In contrast, other epidemiologic studies have been imposed rapidly following other recent disasters without any community engagement and have been plagued with poor participation rates and differential external control groups [30-32]. Also, as hinted by Dominici, *et al.*[1], in their statement “as perverse as it might sound, epidemiologists must view disasters as important opportunities to learn about the etiology of disease”, there are some rather difficult ethical considerations when studying a population that has recently experienced disaster.

Because of the values, responsibilities, and obligations unique to the practice of our profession, it is inevitable that public health professionals will face ethical trade-offs which require that we relinquish one good in order to achieve another we judge of greater value. Defining what is the common good and determining how that shared value should be weighted versus individual goods or rights in the calculus of ethical decisions are among the most critical challenges facing public health ethics. In the context of a community impacted by disaster, this plays out as the issue of when and how to study the impacted population.

In the context of a community study, ethical considerations go beyond the individual and must incorporate the studied community as an independent entity, also[33]. We believe this is even more important with communities recovering from disaster. Such communities should be considered as a *vulnerable population*[34]. Well designed and implemented community based participatory research (CBPR) methods nested within public health service activities can adequately address these complex ethical issues[33]. Epidemiologists and environmental health scientists are not just scientists, but public health practitioners, also. As public health practitioners we are obligated to come to the aid of communities in crisis[35-37], not just study them. Counting the casualties is one of our duties; but our ultimate goal is to limit the toll of the disaster on the life and health of the affected community by providing timely public health assistance [38]. In summary, we believe that a community impacted by disaster should not be asked to participate in research unless the research is secondary to public health recovery assistance, and then ideally instituted through CBPR.

Akin to the CBPR design, it is possible to provide effective and efficient public health service (Community-Based Participatory Service, CBPS) using similar methods of engagement, empowerment, and academic/public health/community collaboration. CBPS is focused on public health action (service) itself, which could motivate research, rather than research to motivate action. This is the fundamental difference between CBPS and CBPR; it is the purpose of the activity that differentiates the two (Figure 1). Scientific knowledge about disease can be learned observationally, without structured human subjects research. Therefore, we believe that by performing ethically conscientious CBPS in response to a technology disaster within a community it is possible to mitigate the toll of the event on the health of the community while concurrently providing generalizable science comparable to that potentially produced by conventional human subjects research methods, such as in CBPR. To accomplish such work unique partnerships of academia and public health with local community organizations are required. We will demonstrate this type of unique partnership within the first several months of the GRACE (*Graniteville Recovery And Chlorine Epidemiology*) project as a case-study, which has produced both successful CBPS and science, and is positioned to eventually generate supplemental CBPR in response to the chlorine gas disaster in the town of Graniteville, South Carolina.

Methods

At 2:48 on the morning of January 6, 2005, a freight train traveling over 77 km/h was inadvertently switched onto an industrial spur and immediately collided with a parked train outside of a textile mill in downtown Graniteville, an unincorporated cotton mill-town in Western South Carolina. The train immediately derailed and one of the derailed cars was punctured and leaked an estimated 54,422 kg of liquid chlorine which quickly boiled and produced a thick cloud of chlorine gas. The weather was calm and the winds were still down in the valley, allowing the plume to spread throughout the community silently while it slept. Chlorine is a strong irritant gas and a weapon of mass destruction first used during World War I[39] and has been used by insurgents in the Iraq war. As a result of the chlorine spill, 9 people died, 72 were hospitalized, and more than 840 people sought medical attention at area hospitals and physicians' offices. At least 220 others experienced symptoms but did not receive medical treatment. The epidemiological response to this event is described in greater detail elsewhere[40-43].

The Department of Health and Environmental Control (DHEC) quickly began to assist the community with their recovery. The environmental side of DHEC was the first group within DHEC to start work on the recovery by helping approximately 875 homes and businesses receive air monitoring and safety inspections before people were allowed to reenter evacuated buildings. But the Graniteville community itself played the key role in guiding the public health recovery work.

DHEC staff was contacted by a Graniteville community leader who asked DHEC to address some of the environmental and health concerns that other leaders and other people had within their community. These voluntary local leaders decided they would form into a group called the Graniteville Community Coalition (GCC) to assist with addressing their community's disaster recovery concerns, which DHEC helped them to establish. The GCC compiled health and environmental questions and concerns from the community into a joint list which was provided to DHEC. DHEC staff took those questions, answered them and developed a fact sheet listing the answers. The GCC determined that they would hold a series of community meetings where citizens could come to have their questions answered. Staffs from both the health and environmental sides of DHEC were asked to be there to answer questions. These meetings were held in Graniteville over a one-week period during March 2005. A community partnership was formed. DHEC, also, had questions that needed to be answered. These included “Did we count all of the casualties?”, “Did everyone who needed medical care receive it?”, “Have all of the surviving casualties recovered from their injuries and illnesses?”. The answer to each was “No.” A few weeks following those initial community meetings, the GCC planned the next steps for DHEC and the GCC: 1) perform additional environmental sampling and monitoring to ensure that the environment was safe; and, 2) establish a community health tracking program. DHEC conducted additional environmental monitoring and sampling and found that the air, water, and soil were all indeed safe. The health side of DHEC designed a comprehensive long-term community health tracking program intended to provide routine medical testing and care for members of the Graniteville community. The proposed design resulted from careful research of the approaches taken to recover from similar environmental disasters in other communities[44-84, 15, 85-93,14, 94, 95, 16-27, 96-97]. As a part of that research consultants within the federal and state government, academia, a private research institute, and international experts on previous disasters[49, 55, 57, 70-73, 75-79, 98-100] were queried about their experiences in disaster recovery and their knowledge of persistent health effects of chlorine gas poisoning. A multidisciplinary academic advisory team was later developed which included some of these consultants and additional scientists from the most proximate schools of public health and medicine. Though early efforts to fund the long-term community health tracking program through the responsible railroad eventually failed, these plans were later modified and incorporated into the DHEC and University of South Carolina (USC) supported health registry and screening projects.

Funds were leveraged within DHEC and through the partnership with USC to begin the health registry and screening projects during the summer of 2005. The goal of these health services was to prevent an epidemic of persistent illness associated with acute exposure to chlorine gas and associated traumatic stress. We believed that by identifying people who were likely experiencing persistent health problems associated with the exposure event we could refer them for local medical care and minimize or stop the progression of their persistent disease and control the epidemic of persistent disease.

We first needed to identify people who were at risk of having yet untreated persistent health problems. Therefore, DHEC developed a completely voluntary health registry open to all persons who lived in, worked in, traveled through, or responded to the Graniteville community on January 6, 2005. Partnering with the GCC, local schools, local businesses, local university (University of South Carolina Aiken), and many local churches, the registry was marketed door-to-door within the communities up to two miles from the accident site, since the closest shelter and decontamination site was located just beyond that distance. In addition, all casualties identified during the response phase of the event were notified by mail about the registry and the health screening to follow. To register people simply called into a local phone number and answered a brief enrollment survey. Most registry telephone operators were raised in the local area and one lost a relative during the event. Additional operators were hired who were fluent in Spanish to allow non-English speaking registrants to enroll. Both within our marketing and upon completion of the enrollment survey, we disclosed that registrants may be eligible for a free health screening and that it was our hope to eventually be able to provide a screening to every registrant. Though the registry opened in July 2005, the primary marketing of the registry began at the community healing picnic, when registry staff from our contractor University of South Carolina Aiken were available on-site to meet with people and enroll them. The registry remains open but was transitioned to the 2-1-1 system after the call volume decreased significantly. The 2-1-1 system, which is staffed continuously by local volunteers and funded by the county, has allowed us to keep the registry open continuously.

To address the issue that many individuals were experiencing problems coping with the traumatic stress that they experienced, the GCC partnered with DHEC and a non-profit, faith-based organization in the community to coordinate a *community healing picnic* immediately before the start of the 2005-2006 academic year. This event was, also, a springboard for both the health registry and health screenings to follow. At this picnic, USC, DHEC, and Department of Mental Health (DMH) social workers were able to talk with residents about their experiences. It also gave trained DHEC and DMH staff an immediate opportunity to offer follow-up to those in need in a safe and comfortable environment. This picnic was full of activities that provided a fun, family atmosphere and was a huge success with more than 850 people attending. The partnership and collaboration on this event began to collectively heal the emotional wounds of this community and to dispel some myths about the town and its future.

Three weeks later in late August 2005 we began 10 weeks of health screenings within the Graniteville community. These health screenings were designed to identify people who *likely* had medical problems associated with exposure to chlorine or traumatic stress which warranted additional care, *not* to diagnose and treat them[101, 102]. The content of the health screenings was determined in consultation with our academic advisory team and the GCC. The health screenings were staffed by local volunteers and contractors and were performed at two area churches (one predominantly black, one predominantly white) and one local medical clinic on a rotating schedule. In brief, the public health screenings included vital signs assessment, medical and exposure histories[103], a focused physical examination, psycho-social health questionnaires[104-107] and consultation with a licensed counselor, lung function and reactivity tests[108], and measurement of an airway inflammation indicator[109-111]. At the close of each screening the results were reviewed by a physician and recommendations were made for follow-up care, when appropriate. A list of available health and social assistance resources within the community and their contact information was provided to all registrants at the close of each screening so that everyone was empowered to pursue the resolution of their most urgent individual health concerns. At the time, all registrants who were exposed within 1 mile from the event were offered a health screening. This public health intervention did not meet the definition of “Human Subjects Research” as defined by 45 CFR 46.102(d) and determined by the DHEC and USC institutional review boards (IRBs). All registrants voluntarily agreed to participate in the public health screenings. Each screened registrant first provided their informed consent, or in the case of children, parents provided informed consent in proxy. All volunteers/contractors complied with DHEC's Confidentiality Agreement and were either HIPAA certified or trained. Lung function testing is very safe and performed routinely, though has some risk. A crash cart and physician were available on-site at all times for any unexpected complications. Lung reactivity testing was provided only to those who demonstrated a potential clinical benefit from it and was performed during a follow-up evaluation at a local hospital due to the increased risks with that test.

Results

The Graniteville Health Registry represents the greater Graniteville community. The registry is 50% female, 69% white/Caucasian, 26% black/African-American, 0.7% Native American, and 1.7% Hispanic/Latino. These figures are almost identical to the resident population of Graniteville according to Census 2000 data (Table 1). Compared to Census 2000 data, the registrants were slightly older with slightly fewer children and more seniors. Screened registrants were also older, though comparable to the parent population in most all other demographics. The peak level of education within adults over 25 years who were enrolled in the registry was nearly identical to the Census 2000 data for both the high and low education levels. A higher percentage of registrants were high school graduates, but fewer had some post-high school education. Participation rates were stable across the community and exhibited a randomly scattered spatial distribution across the Graniteville area (Figure 2).

Our participatory public health services have enabled us to gather a more accurate count of the casualties from this disaster, to identify casualties likely to require additional medical care and refer them for that care, and to promote health and prevent the progression of persistent disease within community members. Through the health registry we have identified 197 previously unreported casualties who sought medical care for injuries and/or illnesses which occurred or were worsened during the disaster. Between the casualties identified during the response and recovery phases, we currently are aware of 1,384 casualties from this event. Of those, 958 have enrolled in the health registry. There were 259 registrants who received a health screening at 8-10 months post-event. As a result of the initial health screening, we identified 142 casualties (55%) who likely needed additional care, provided them with their medical records from the health screening to support that determination, and referred them for additional medical treatment. The remaining 117 screened registrants were relieved that there were no current medical concerns observed during their screening that warranted immediate additional follow-up care. During the initial screening, 19% of the registrants screened were recommended for additional pulmonary care based on their pulmonary function, inflammation, and reactivity testing results (Table 2). Prior to the health screenings the medical concerns of some registrants were underappreciated by local physicians due to their skepticism of the validity of reported symptoms due to the litigious environment following the disaster. The objective medical testing results from the health screening empowered community members to rebut concerns about the validity of their health problems and promoted their ability to regain control of their health and to prevent their continued morbidity.

By employing a conscientious CBPS strategy without complex population sampling methods or obligation, we have enrolled a population within our health registry that is representative of the population we sought to serve. The registrants were randomly distributed within the community, indicating that chlorine and traumatic stress exposure were, also, randomly distributed within the community. Furthermore, because we did not limit registry enrollment geographically *a priori*, registrants who were located on the outer fringe of the community at the time of the event and likely were not significantly exposed could serve as internal controls for any supplemental epidemiologic study. Since such potential internal controls were selected with the same criteria as the exposed persons, there is little likelihood of selection bias[112]. Furthermore, using an internal control group within a follow-up epidemiologic study could disentangle the effects of chlorine from the effects of traumatic stress within the disaster because both the internal control group and the chlorine exposed group would have been exposed to the traumatic stress of the event while an external control group would not. This population based sample could serve as a study population in supplemental CBPR if the community should choose to do so.

Discussion

The GRACE project has demonstrated the successful application of CBPS following a technology disaster within a community. In addition to our project goals of assisting with the recovery of the affected community, we have developed a population based registry, which could eventually serve as a study cohort. Because the registry so well represents the parent population and registrant locations during the disaster were scattered randomly across the community, we further conclude that the registry is comparable to a random sample from the parent population. Essentially, the GRACE project has demonstrated that by performing thoughtful CBPS with the primary goal being to serve the population affected by disaster, it is simultaneously possible to generate similar science that is sought from a traditional investigator-initiated “natural experiment design” disaster epidemiology study, but without actually performing any human subjects research.

However, our CBPS approach has some limitations. Because enrollment in our registry was voluntary, many people who we identified in the response phase have not registered. Some of them were lost to follow-up. Because 62% of the known victims who chose not to register had received medical care within a hospital immediately following the event, we believe that many of those who have not enrolled in the registry chose not to because they did not believe that it would help them since they were already well aware of their current health and were receiving sufficient medical care. This means that our estimates of disease prevalence from the registrants alone are likely to underestimate the real prevalence of persistent disease within the Graniteville community. The health screening was primarily targeted to help the casualties of the event who were unaware of or dissatisfied with their current health status, and the registry was used as a conduit to identify that target population. The registry was never intended to include every casualty from the event. As a consequence, we are still unable to accurately estimate the true prevalence of disease within this community through the data collected from the health screening alone. Further public health surveillance is needed to better estimate the true prevalence of persistent disease within the Graniteville community.

We would have liked to have done more active surveillance of persistent disease within the Graniteville community but we were limited by our resource capacity, both human and financial. DHEC had no prior funding dedicated to assist with the recovery and surveillance of communities impacted by technology disasters. It is important to note that the responsible railroad has been supportive of our public service activities, though they did not chose to fund them. We believe, however, that financial support by the responsible railroad could have undermined the trust of the community in the CBPS. Furthermore, any medical knowledge which could have been gained from those efforts could have potentially exhibited a conflict of interest, and been distrusted or even discounted by treating physicians. In addition, the knowledge that the railroad was financially supporting the public health activities might have elicited further distrust in the activity within the community, reduced participation rates and found our GRACE team guilty by association.

We believe that there is a general gap in the understanding of the profound differences between bioethics and public health ethics among most IRBs and epidemiological researchers. Within public health, the ethical value of respect for persons is expanded to respect for communities[33]. This implies a respect for the community's will and self-determination, though discerning the will of the community and determining who speaks for the communities are not easily ascertained. The individual ethical value of respect for dignity also carries the broader sense of respect for cultures and communities so that public health actions are sensitive to groups, especially vulnerable populations. The respect for dignity within a vulnerable population is dramatically illustrated in communities impacted by disaster. We believe that by incorporating CBPR types of strategies into public health disaster recovery activities it is possible to address these very complicated ethical issues while still fostering valuable services and science while potentially serving as a foundation for later research.

Conclusions

The scientific heritage of Hiroshima and Nagasaki demonstrated effective implementation of CBPS which later led to copiously productive CBPR. The GRACE project has followed that example, and demonstrated how thoughtful CBPS can both assist the community affected by disaster and advance scientific understanding of the health effects of such an event on the impacted community all without initially performing any human subjects research. Such work could serve as a foundation for supplemental CBPR.

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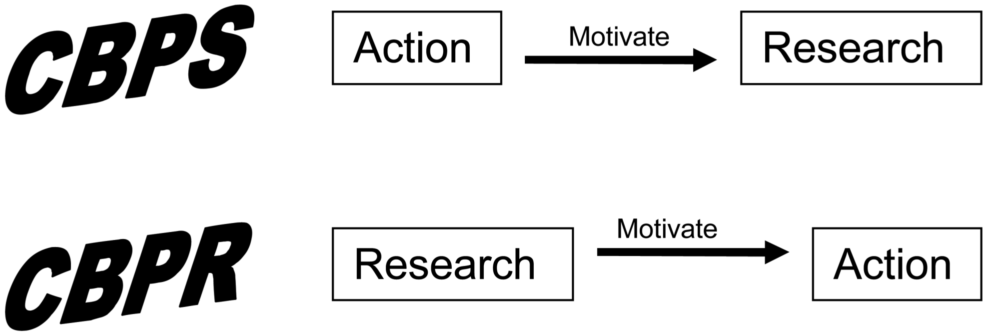

Figure 1.

Diagram Contrasting Community-based Participatory Service (CBPS) with Community-based Participatory Research (CBPR)

Figure 2.

Map of the Spatial Distribution of the Addresses of GRACE Registrants

Table 1

Demographic Comparison of the Graniteville Population

	Graniteville*	Registry	Screened
Population size	7,009	958	259
Age under 5 yrs., %	8.4	4.4	3.5
Age under 18 yrs., %	29.8	20.5	17.0
Age 65 yrs. and over, %	12.0	15.7	20.5
Female , %	52.0	51.0	55.6
Race, White , %	69.6	68.9	63.6
Race, Black or African American , %	26.9	25.6	31.8
Race, American Indian and Alaska Native , %	0.6	0.7	0.8
Race, Asian , %	0.3	0.0	0.0
Race, reporting some other race, %	1.5	1.5	0.8
Race, reporting two or more races, %	1.2	0.5	0.4
Race, Hispanic or Latino, %	2.1	1.7	3.1
Speak Spanish	2.8	1.1	1.9
Less than 9th grade, % of age 25+	9.6	9.9	10.3
9th to 12th grade, no diploma, % of age 25+	19.1	20.5	20.1
High school graduates, % of age 25+	34.8	41.1	39.7
Some college, no degree, % of age 25+	20.9		
Associate Degree, % of age 25+	7.5		
Some college/Associates degree, % of age 25+		18.5	22.1
Bachelor's degree, % of age 25+	5.3	7.0	5.4
Graduate or Professonal degree, % of age 25+	2.8	2.9	2.5

*Census 2000, US Census Bureau

Table 2

	n	**%**
Total	142	54.8
Pulmonology	48	18.5
Psychiatry/Psychology	47	18.2
Ophthamology	19	7.3
Dermatology	14	5.4
Otolaryncology	7	2.7
Cardiology	6	2.3
Neurology	3	1.2
Other	86	33.2