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Tangible Evidence, Trust and Power: Public Perceptions of Community Environmental Health Studies

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Abstract

Communities with environmental health concerns in the USA frequently request studies from their local or state departments of public health. This paper presents findings from three focus groups conducted in communities north of Boston that have been the subject of two different environmental health studies. The focus groups were designed to elicit residents' perceptions of environmental health, and of the particular studies conducted in their communities. In all focus groups, participants had difficulty accepting the findings of health studies that contradicted their own experiences of environmental exposures and illness. Our results suggest that lay knowledge, informed in varying degrees by the experience of what we term "tangible evidence," creates a lens through which communities interpret a health study's findings. The differences in reliance on tangible evidence were related to participants' sense of trust in public officials, and the institutions responsible for conducting health studies. Participants from the wealthier, predominantly white communities discussed trust in study design and methodologies used. In contrast, participants from the lower income, higher minority communities assessed health studies with reference to their trust (or lack thereof) in study sponsors and public health institutions. Participants' experience of tangible evidence, trust or distrust in health agencies and research institutions, and a sense of relative community power, influence how they assess the findings of environmental health studies and may have implications for public health.

Keywords

USA; environmental health; environmental justice; focus groups; lay knowledge; power; trust

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INTRODUCTION

Communities affected by pollution and concerned about environmental hazards frequently request health studies from their local or state departments of public health, but are often frustrated with the results. Case studies of communities living with contamination have highlighted residents' distrust of health studies and the public health agencies that conduct them (Brown & Mikkelsen, 1990; Edelstein, 2004; Levine, 1982). While researchers continue to improve the scientific methods used in health studies, there has been little effort to determine how and by what measures affected communities judge the quality and meaning of these studies. Local or lay knowledge plays an important role in shaping people's perception of environmental health *risks* (Corburn, 2005; Fischer, 2000; Tesh, 2000). Also, risk perception is influenced by people's perceived credibility of institutions responsible for protecting public health (Waterton & Wynne, 1999).

This paper reports on focus groups conducted with residents of communities north of Boston, Massachusetts that had recent experience with health studies. The three focus groups were designed to elicit community perceptions of environmental health in general, and of the particular studies conducted in their communities. Specifically, they were designed with the perspective that people who live in different settings (e.g., towns with different racial compositions and socioeconomic environments) may have different social constructions of knowledge, and that social and structural, economic and environmental factors shape perspectives on health, environment and science (Rose, 1997). The factors found to be relevant in this study are the differences between areas considered to be environmental justice communities (i.e., with higher burden of environmental exposure, as well as a lower-income and/or higher-minority population), and communities that are not environmental justice areas.

The unique concerns of environmental justice communities, including multiple and complex social and environmental exposures, and a history of mistrust with government agencies, led us to compare perceptions of health studies in communities considered to be environmental justice areas to communities that are not. We chose focus groups as our research technique because it is a very appropriate way to answer research questions about factors that influence perceptions of environmental health and of scientific knowledge. Such questions include: Does the effect of influencing factors differ among groups or settings? Does living in a low-income area with a higher percentage of minority residents and environmental hazards influence perception of environmental health and health studies? In order to frame this project, we provide background on environmental justice and health disparities, and on lay knowledge vs. scientific knowledge.

Environmental Justice and Health Disparities

In the US there are persistent and growing disparities in mortality, morbidity, and disability between whites of high socioeconomic status and people of color who are lower-income (Brulle & Pellow, 2006). Of particular interest to scientists in the field of environmental health are the physical, biological and chemical hazards that are, in theory, avoidable exposures (e.g., hazardous waste sites, and sources of chemical contamination) and that could potentially result in health inequalities (Mackenzie, Lockridge & Keith 2005; Morello-Frosch & Jesdale, 2006; Wing, Cole, & Grant, 2000). Two decades of research have documented the extensive burden of environmental pollution in low-income communities and communities of color in the US (Bullard, 2005). A recent study in Massachusetts reported that lower-income communities face four times the amount of exposure to environmentally hazardous facilities and sites than higher-income communities. Additionally, higher percent minority communities face over twenty times the exposures to environmental hazards than lower minority communities (Faber & Krieg, 2005). A similar pattern of disproportionate exposure to

environmental hazards among those who are less politically powerful, nonwhite, and poor is apparent worldwide (Coughlin, 1996).

According to Logan and Molotch (1988), low-income communities are more vulnerable to negative impacts of undesirable economic activities, such as sources of industrial pollution, in part because they lack the political power that could offer them influence with business elites. Power is described as the overall political and economic position of a community in relation to elected officials, business, or corporate activity. The relationship between power and environmental justice has been demonstrated in a small number of studies in which disparities in political power are identified as a contributing factor to environmental inequalities (Morello-Frosch, Pastor, Porras, & Sadd, 2002). Many environmental justice activists are convinced that hazardous exposures that are the consequence of environmental injustices are responsible for the “egregious disparities in health by race/ethnicity and social class” (Shepard, Northridge, Prakash, & Stover, 2002, p. 139). It follows that residents in communities with toxic waste sites often distrust elected and appointed public officials who they blame for failing to protect public health (Edelstein, 2004).

Environmental justice scholars, researchers and activists have argued that one way to develop effective public health policies, mitigate the effects of environmental injustice, and to build trusting relationships between public health experts and the public may be to involve residents from lower-income, higher-minority areas in environmental health research (Macaulay, Commanda, Freeman, Gibson, McCabe, Robbins, et al., 1999; Northridge, Yankura, Kinney, Santella, Shepard, Riojas, et al. 1999; O’Fallon, Tyson, & Dearry, 2000; Quigley, Handy, Goble, Sanchez, & George, 2000; Shepard et al. 2002; Wing, Grant, Green, & Stewart, 1996). In 1999, the Institute of Medicine (IOM) published *Toward Environmental Justice: Research, Education, and Health Policy Needs* (1999). This report advocated “participatory research” as a method for addressing health disparities and environmental injustice. This was an important validation of community participation in an arena where scientific studies--specifically epidemiologic studies and risk assessments which traditionally allowed little opportunity for meaningful community input--had been the basis of policy decisions that contributed to environmental injustices. By endorsing participatory research, the IOM report also was an acknowledgment that community participation in research may increase the ability of society to collectively tackle public health problems. Community-based and participatory research methods tap lay knowledge of disease and environment allowing for a mutual exchange of lay knowledge and scientific knowledge between residents and professionally trained researchers, neither of which would be accessible to the other without collaboration (Israel, Schulz, Parker, & Becker, 1998; Scammell & Dearry, 1997; Shepard et al. 2002).

Lay Knowledge v. Scientific Knowledge and Environmental Health Studies

Debates regarding the role of expertise in democracy have been ongoing for centuries (Collins & Evans, 2003). A theme in this debate is the distinction between lay and professional or scientific knowledge (Brown, 1992; Humphreys, 2004; Moffatt & Pless-Mulloli, 2003; Schutz, 1953). Scientific knowledge is academically derived by credentialed individuals and institutions, and grounded in theory or scientific principles. Lay knowledge is grounded in day-to-day, concrete experience. However, lay and scientific knowledge should not be construed as monolithic or mutually exclusive; individuals may possess more than one type of knowledge (Corburn, 2005; Fischer, 2000). Lay knowledge of environmental hazards and disease is often the impetus for environmental health studies. However, beyond the initial observation of a problem, lay knowledge is often excluded from the process of designing research, generating and analyzing data. This creates a ripe environment for conflict in interpretation and confidence in study results. This tension in types of knowledge and approaches to problems is seen between scientists and residents known to have conflicting perspectives about how to investigate

community environmental health concerns, and among policy makers aspiring to make evidence-based decisions (Brown, 1993). Investigations conducted by university researchers, local or state health departments usually draw upon sources of data and employ methods viewed as legitimate by the scientific community (e.g., peer reviewed studies, databases, registries). Such data sources and methods yield findings or evidence that conform to scientific and, in some instances, legal standards (Corburn, 2005). Further, so-called scientific evidence gathered via these methods may contradict evidence that is lay-derived or more tangible, i.e., that may be smelled, touched or seen. In this paper we examine how members of the public invoke this kind of sensory experience of environmental health, what we term “tangible evidence.”

This paper also contributes to the literature on the public understanding of science, a field of research that examines public perceptions, understanding and attitudes towards science and technology, with a particular focus on how lay people translate or understand scientific information. In a well-known study conducted in England, Wynne (1996) analyzed how Cumbrian sheep farmers understood and responded to officials’ attempts to control the sale and movement of radiation-contaminated sheep in the wake of the Chernobyl disaster. The study highlights the far more sophisticated understanding by sheep farmers of their environment than scientists or government officials ever took the time to acknowledge or appreciate. Further, by not engaging the sheep farmers in their investigation of contamination and in discussions of scientific uncertainty, and by instead telling the farmers authoritatively how to manage their herds, the scientists overlooked important facts known to the farmers that would likely have influenced their recommendations. Wynne’s study, like many in the field, revealed a complex set of social issues related to trust and credibility in scientific information and the social relationships, networks and identities from which trust and credibility are derived.

BACKGROUND

On the North Shore of eastern Massachusetts, in the City of Salem, is the Salem Harbor Station, a coal-fired power plant that has been dubbed by environmental health activists as one of the “Filthy Five,” one of the five worst-polluting coal or oil fired power plants in Massachusetts. The suburban towns of Marblehead and Swampscott lie directly opposite the harbor from the Salem Harbor Station.

Compared with the State of Massachusetts as a whole, Salem and the neighboring City of Lynn have below average median household income and a higher-than average percentage of non-white Hispanic or Latino residents. In contrast, the towns of Marblehead and Swampscott have higher than average median household incomes and populations that are nearly 100% white according to the US Census (Bureau, 2002). Both Salem and Lynn are identified as among the top twenty towns most extensively burdened by environmental hazards (Faber & Krieg, 2005). Marblehead and Swampscott are not.

Community Environmental Health Studies

In 1997, the Massachusetts Department of Public Health (Mass DPH) released *Cancer Incidence in Massachusetts 1987–1994: City and Town Supplement* (1997). The report, which was based on data from the state cancer registry, found statistically significant elevations for breast cancer, leukemia and melanoma in Marblehead, and for breast cancer in Swampscott. The report indicated significant elevations for pancreatic and lung cancers in both Salem and Lynn, but no significant elevations for breast cancer, leukemia or melanoma (Massachusetts, 1997).

The same year, concerned residents of Marblehead asked their state legislator and their local Board of Health to request a follow-up study from the Mass DPH. In response, Mass DPH conducted a “descriptive evaluation,” or cross-sectional study (hereafter the Mass DPH study) that compared cancer incidence in Marblehead and Swampscott at the census tract level with population characteristics and environmental exposures, including emissions from the Salem Harbor Station. Although Salem is home to the Salem Harbor Station, neither Salem nor Lynn was included in the Mass DPH study. The study examined only the cancers that were elevated in Marblehead, and included Swampscott where breast cancer was also elevated. The Mass DPH study found no pattern of increased cancer incidence in the census tracts that are downwind of the Salem Harbor Station, the areas thought to experience the greatest impact of power plant emissions (Massachusetts, 1999).

A second and separate study was conducted on respiratory and cardiac health outcomes with support from the Pew Charitable Trusts. Researchers from Harvard School of Public Health used a computer model to estimate the health effects of emissions, and projected benefits of emission reductions, from two power plants in Massachusetts including the Salem Harbor Station. The model estimated that within New England, eastern New York, and New Jersey, emissions from the Salem Harbor Station were annually responsible for 53 premature deaths, 570 emergency room visits, 14,400 asthma attacks, and 99,000 daily incidents of upper respiratory symptoms. The modeling predicted that per capita health risks were greatest near the power plant and decreased with distance from the source (Levy, Spengler, Hlinka, & Sullivan, 2000). The study did not look at possible cancer risks.

In summary, two different agencies (a private university and a state health department) conducted two different types of studies on the potential for health effects associated with the Salem Harbor Station. The Harvard study estimated health effects associated with the power plant, while the Mass DPH study did not find an association between the power plant and health. The Harvard study looked at respiratory and cardiovascular outcomes, while the Mass DPH study examined cancers. Findings of both studies were communicated to the public via articles in local and regional newspapers, public forums and by the efforts of HealthLink, a community-based environmental health organization formed in 1998. Prior interviews with HealthLink activists revealed that there had been confusion about the study findings among area residents. This study sought to assess how residents perceived the findings and relevance of the two studies, and whether there were any differences in perceptions among the surrounding communities.

METHODS

This study used focus groups as its primary data collection technique. Group interviewing is an alternative to one-on-one interviewing when the object of research is to explore attitudes or reactions of a group or community in response to some commonly experienced aspect of their environment (Ulin, Robinson, & Tolley, 2005). In response to questions from the moderator and comments from other participants, focus group participants offer insights on the perspectives of the community, revealing clues to the social contexts that shape their opinions.

Recruitment

A total of three focus groups were conducted in the last months of 2003. Because the racial and socioeconomic demographics of Marblehead and Swampscott are very similar, and they were also the two towns included in the Mass DPH study, we conducted a single focus group with residents of these two towns. Salem, where the power plant is located, has very different demographics than Marblehead and Swampscott and more closely resembles the demographics of neighboring Lynn. We conducted a second focus group with residents of Salem and Lynn,

neither of which was included in the Mass DPH study, but whose residents might logically have shared concerns about the effects of the power plant.

In addition to the considerations of town of residence, race or ethnicity, and income, this study examines how various levels of knowledge may affect attitudes (e.g., those who are very knowledgeable about the studies conducted in their area versus those who know nothing about the studies). A third focus group was conducted with members of the public known to have been informed about the studies (because their names appeared on mailing lists or public meeting rosters) but distinct from the general public which may or may not have interest in environment and health issues (Krimsky & Plough, 1988). The three focus groups are as follows [See Table 1: Focus Group Demographics]:

1. **Informed Group:** We recruited residents of Salem, Lynn, Marblehead, and Swampscott who were likely to have followed environmental health issues closely. Participants were randomly identified from a database of nearly 1000 people who attended one or more meetings, hearings, or public forums about the power plant or the health studies, and signed a public roster or attendance sheet; or who signed up to receive mailings from HealthLink, the largest community-based environmental health organization in the area. Eight people participated in this focus group, all of whom identified themselves as White or Caucasian.
2. **Salem Group:** We randomly recruited residents of Salem and Lynn. Seven people participated in this focus group, six of whom self-identified as White or Caucasian, and one of whom identified himself as Black.
3. **Marblehead Group:** We randomly recruited residents of Marblehead and Swampscott. Seven people participated in this focus group, six of whom self-identified as White or Caucasian and one of whom self-identified as Jewish.

Potential participants for the Salem and Marblehead focus groups were identified using random digit dialing. Participants were contacted via telephone by trained project staff and screened for eligibility. Persons under age 18 or living less than four years in the area were deemed ineligible. Personal invitations confirming participation, location and time of the group (with maps and contact information) were mailed 10 days ahead of time.

In the initial telephone calls all candidates were asked for self-identified race or ethnicity and educational attainment. For the Salem group, we over-recruited non-white participants and included a Spanish speaking recruiter so that participant demographics would reflect the cities of Salem and Lynn. Despite these efforts, participants in all three groups were overwhelmingly white and middle- or upper income, and women outnumbered men by nearly 3:1. Further details on recruitment are available by request. We discuss the implications of our participant demographics later in the paper.

Focus Group Procedures

Focus groups were located in places that were convenient for participants (i.e., free parking, safe, familiar, accessible to people with physical disabilities) and included an adequately sized room so that everyone was comfortable and could hear each other well. In all instances there was a large table(s), assurance of privacy and no interruptions, low-noise, bathrooms near by and a place for serving food and drinks. Participant perception of the meeting location was also considered. We looked for frequently used or well known historic buildings and avoided buildings that housed overtly partisan or religious organizations.

Each focus group was moderated by a trained facilitator and observed by one or more project staff who also served as note-taker. Informed consent, as approved by the Institutional Review

Boards at Boston University Medical Campus and the University of Medicine and Dentistry of New Jersey was obtained from each participant prior to each focus group.

All focus groups were conducted using a discussion guide designed by the project team to explore participants' knowledge, perceptions, and beliefs about environmental health issues generally, and the studies that had been done in their area more specifically. Early questions were broad and open-ended (e.g., "When you think of the area where you live, what comes to mind when I say 'environmental health'?"). Once it became apparent that participants were comfortable speaking candidly, questions became narrower and focused on the findings of the particular studies and the methods they employed. To stimulate discussion, participants were presented with one-page summaries of the studies and asked to share their reactions. Finally, preferences about how participants would like to see health studies conducted, and expectations they held for community involvement in research were explored. Throughout the groups, participants offered insights on the perspectives of the community, revealing clues to the social contexts that shape their opinions.

Data Analysis

Focus group proceedings were recorded and transcribed; all identifying information was removed, and participants were assigned pseudonyms. Seven members of the research team reviewed portions of the transcripts to develop a list of analytic codes based on key words and phrases in the transcripts (Ulin, Robinson, & Tolley, 2005). Codes are words and phrases that enable analysts to retrieve codes and associated data, determine frequency, presence or absence, and relationship with other codes (Bogdan & Biklen, 1982; MacQueen, McLellan, Kay, & Milstein, 1998).

Approximately 80 codes were identified by members of the research team following an initial review of the group transcripts. We discussed the meaning of each code and identified major and minor codes. These major codes followed the primary questions in the focus group discussion guide. The resulting codebook included the code; a definition of the code including guidelines for when and when not to use it; and in some instances, an example of text that would be tagged with that particular code (MacQueen, McLellan, Kay & Milstein, 1998). The codebook is available upon request.

Three members of the team then coded the same portion of a transcript. We met and compared coding to assess the reliability of the codebook and agreement among coders. Once it was established that coders were in general agreement, two of the three team members coded the remaining focus group transcripts using the software package NVivo developed by QSR International.

We used analytic induction, also known as deviant case analysis, to identify themes and closely examine instances that did not fit our emerging theories (Frankland & Bloor, 1999). This was done by coding data to identify and include the exceptions, misfits, and 'negative' examples, which often tell analysts as much about the themes of the project as do the incidents, events, and units of data that "fit" codes well (Coffey & Atkinson, 1996). This was helpful in making sense of the role individuals played in focus groups, especially where the loudest voices were not representative of the general group response to questions.

After all transcripts were coded, it was clear that some of our codes suggested concepts that would become the framework of our analysis. For example, "tangible evidence" and "common sense" were separate codes initially tagging specific references in the text. "Tangible evidence" was the code for "how people see, feel, taste, problem; sensory/lived experience of an environmental or health problem," and "common sense" coded "all references to common sense or findings that are identified as obvious or intuitive." Close examination of these and

other codes, and the meaning of their relationships, became the basis of our findings of tangible evidence, trust and power.

FINDINGS

Focus group findings are organized around the concepts of tangible evidence versus scientific evidence, perceptions of trust or distrust in health agencies and research institutions, and relative community power. Participants' experience of tangible evidence, trust and power, were different among people who live in environmental justice communities compared with those who do not. These differences also influenced how participants assessed the findings of environmental health studies.

Tangible Evidence v. Scientific Evidence

“Tangible evidence” includes descriptions offered by focus group participants of an exposure or environmental threat, such as the visible presence of the power plant and soot described by Katy in the Salem group: “It’s floating in the air, you are breathing it, you are wiping it off your white furniture, your ceiling.” Tangible evidence also includes first-hand knowledge of disease or illness such as that described by Marilyn in the Marblehead group: “I lived on a street where there was a fairly unusually high number of women who had breast cancer, myself included.”

These personal and sensory encounters influenced people’s perceptions of environmental health and opinions of the studies conducted in their communities. The influence of tangible evidence was most apparent among participants in the Salem group, comprised of residents of the overburdened communities with a high percentage of low-income and minority residents.

Salem group—In all three groups, environmental health was a familiar concept. All participants understood that environmental hazards may be associated with health problems. However, participants in the Salem group immediately linked specific environmental exposures with health outcomes in their own community (e.g., soot and asthma) prior to having reviewed either of the study summaries. Of all three groups, the Salem group expressed most clearly that tangible evidence influenced their perception of environmental health concerns (i.e., specific environmental exposures associated with health outcomes). When the facilitator asked about environmental health issues in their community, the first person to speak said, “the electric company and the soot that comes out from it, and a higher rate of bronchitis in Salem because of it.” A discussion ensued involving nearly all Salem group participants demonstrating that encounters with environmental pollution, particularly soot from the Salem power plant, anchored a shared conviction that they were facing increased incidence of health problems such as asthma and cancer.

Tangible evidence also influenced participants’ reactions when presented with summaries of the findings from health studies. Four of the seven Salem group participants immediately responded to the summary of the Harvard study (predicting health effects associated with the power plant), drawing directly on their own experience, or tangible evidence. Sarah stated that the estimated respiratory health outcomes were not surprising to her because her son suffered from chronic lung infections. Caroline also agreed with the results because they confirmed her experience of chronic bronchitis. James disagreed with the Harvard study’s conclusion that particulates fall closer to the source and cause the most damage to those who live nearby. His logic was based on his own contradictory experience of living near a facility where, “the kids living there around the chimneys didn’t get sick. But people around 50 kilometers, or 30–35 miles or 100 miles get sick!” Stephanie disagreed with James, also drawing on her own experience: “[I]t makes sense to me that particulates would fall closer to the source, speaking as someone who lives very close [to the power plant].” In all instances, participants in the

Salem group--the residents of lower income communities with high environmental burdens--drew from their own tangible evidence to judge the findings of a study based on how well, or not, the study results corroborated their experience. The Salem group distinguished themselves by their reliance on tangible evidence over study findings.

Informed group—Participants in the Marblehead and Informed groups did not talk as much about their own experience when discussing environmental health concerns, nor were they as quick to link specific exposures to illness. In the Informed group, for example, only one participant attributed her interest in environmental health to her experience as a parent of a child with a disability. No one in the Informed group linked a particular environmental concern with a specific illness (e.g., soot with asthma) prior to reading the study summaries. The Informed group, however, very clearly identified the difficulty trying to reconcile the findings of scientific studies that contradicted lay knowledge.

After reading the summary of the Mass DPH study, some participants in the Informed group struggled to believe the finding that there was no relationship between the power plant and cancer:

Alex: It would seem to me that if, especially regarding the power plant, as much as I think there may not be a correlation [between illness and emissions]...I don't know. I think there still may be... And it seems to me that the physical evidence of stuff all over the car, stuff in the house...

Priscilla: ...can't be good. It can't be good for us.

These participants were hesitant to accept the negative findings of the Mass DPH study, and referred to tangible evidence of what they believed to be proof of environmental health harm.

Marblehead group—As with the Informed group, participants in the Marblehead group (i.e., residents of the wealthier, predominantly white towns of Marblehead and Swampscott) rarely mentioned their own experience of physical or tangible evidence (e.g., soot in the house or on the car) when discussing particular study findings. However, they did refer to “common sense” and “common thought,” implying that their assessment of study findings was also shaped by a type of shared experience or lay knowledge. Aaron, in the Marblehead group, responded to the summary of the Harvard study, saying, “[I]t is essentially a statement of common sense principles.” Aaron also identified the tension that exists between different ways of knowing, tangible evidence or common sense versus scientific knowledge:

We know by common sense why we have higher [asthma] rates, because there's a power plant that's dirty next to us... These studies, although they may be interesting to do and are informative in some way, in the end you are going to rely on common sense because science has its limits.

Similar to the Informed group, participants in the Marblehead group did not initially link specific environmental exposures to health outcomes. One participant, Marilyn, described her personal experience of breast cancer, but did not associate the cancers in her community with the power plant. Another participant, Deborah, knew people from Marblehead who had had breast cancer but stated that she was not able to “make a direct correlation between the two things: between the power plant and [the cancer].” Deborah also described a friend in Marblehead, saying: “From her balcony you could see the power plant. Fortunately she is very healthy, but I would think that the impact would be more within that neighborhood.” Deborah's suggestion that the view of the power plant from her friend's home might be evidence of a health threat was challenged. One person used the example of acid rain to argue that what can not be seen may be more harmful than what is visible (i.e., the power plant). This was the only

instance in any of the focus groups when someone challenged conclusions drawn from the immediate or personal experience of tangible evidence.

Whether perceived as common sense or tangible evidence, the conflict between lay knowledge and scientific evidence existed in all three groups. The struggle to reconcile conflicting types of knowledge, lay and scientific, was most apparent among participants in the Informed and Marblehead groups. In contrast, participants in the Salem group relied more readily on their own experience, without any apparent struggle to reconcile the types of knowledge. Instead they were adamant in their opinions of the study findings based on tangible evidence.

Trust and Perception

In all three focus groups, trust influenced how respondents interpreted the health study findings. However, the groups differed with respect to where they placed the importance of trust. The Salem group (the environmental justice communities) voiced more concern with trust in the people and agencies that conduct studies, whereas the other groups were more concerned with trust in study methods.

Salem group—In the Salem group, discussion about the studies usually evolved into a discussion of the trustworthiness of study sponsors. One Salem resident, Dottie, did not know how to respond to the Mass DPH study because, “It is something about studies; there is always a political element involved, because a lot of things are not reported accurately and they are slanted.” Janet explained that because Massachusetts is a “business-friendly” state, she is not inclined to believe findings from government studies. Sarah agreed, claiming that health and education were not a priority of the administration, “[I]t obviously all revolves around money.” Stephanie added:

I think who is supporting [a study] is important. Like, you read a story that chocolate is good for your teeth and then you hear it is put out by the Candy Manufacturers of America.

When asked directly what would make a study *bona fide*, Caroline said it should be done by “an independent group of people who aren’t owned by anybody.” Janet suggested that universities may be more trustworthy as study sponsors but James disagreed, “To say [Boston University], [Massachusetts Institute of Technology] or Harvard should come in and do the study, these are not trustworthy people!” Stephanie reiterated her belief that whoever conducts a study, trust in results is determined by “who is funding that particular study.” Participants in the Salem group were generally of the opinion that financial and political interests may outweigh even the most careful scientific methods.

Marblehead group—In the Marblehead group (residents of the more affluent areas) the topic of trust only came up in direct response to questions from the facilitator. When mentioned, trust was in reference to the study designs. Aaron said that although he liked the results of the Harvard study better than the Mass DPH study, he did not approve of the modeling methodology, “If you don’t like the methodology then you can’t trust the results.” Reactions to the study summaries were focused largely on methodological concerns. For example, speaking of the Mass DPH study Jonathan said:

If there was some big problem, it may have shown up, but just because it didn’t show up doesn’t mean that it is not there either... It could still be a problem and not get caught in the statistics due to the limitations of statistical studies.

Only Marilyn in the Marblehead group expressed skepticism about a study that was not a purely methodological concern:

To me, honestly... to me it looks as if somebody from the coal industry or the power plant industry was standing in the back saying, “No, no, no, no! No cause and effect is to be established here!”

Most other participants in the Marblehead group ignored Marilyn’s concern. Only Aaron responded, “I don’t think there is any grand conspiracy.” With the exception of Marilyn, participants did not spend much time discussing the credibility of the researchers or institutions conducting the studies. In a discussion about the utility of health studies and who should be involved, Jonathan summarized the group’s focus on methodology, “ultimately it comes down to designing a good study.”

Informed group—The Informed group, composed of residents from all towns (Marblehead, Swampscott, Salem and Lynn), considered a variety of concerns that were similar to those addressed in both the Salem and the Marblehead groups. The Informed group spent a lot of time grappling with how to determine whether a study is trustworthy or credible, and also addressed how the types of information or knowledge in the study design, and social factors such as the trustworthiness of the study’s sponsors, would contribute to overall confidence in the study’s findings.

With regards to study sponsorship as an influencing factor on study quality, participants in the Informed group debated which universities in Massachusetts were more trustworthy and which were more ideological, why a university would or would not be more objective than the government, how each is funded, why concerns regarding job security may influence studies, and how politics influence findings. Participants in the Informed group agreed that to mitigate the influence of money and politics, “multiple checks and balances” are important. In the Informed group, Deirdre—one of two participants in the Informed group who was from Salem, home of the Salem Harbor Station—strongly expressed her lack of trust in government generally. This mistrust affected her reading of the Mass DPH study findings:

It is hard for me to trust somebody... I don’t know who conducted the study, how it was conducted... what their agenda is, and what their vested interests are.... I don’t know who controls the Marblehead Board of Health or who pays in to support what representative... or where the potential biases are.

Had Deirdre been in the Salem group, her comments may have been received with agreement. However, her comment elicited little response from participants in the Informed group. Joe asked why elected officials could not be trusted to oversee a study and “determine whether it was an accurate study or not?” None could respond to this question, or agree on which organizations and individuals were trustworthy enough to play this role.

Despite a long discussion about the credibility of research agencies and institutions, the Informed group overall tended to assess the quality of a study based on scientific and methodological considerations. However, they lacked technical knowledge to critique the scientific methods. Informed group participants voiced a preference for “control studies,” “blind,” or “double blind” studies. When asked by the facilitator what would make a good study, one participant responded with “placebo,” a term generally reserved for clinical trials although the appropriateness of this comment was not discussed. There was also debate over whether or not a computer model that generates statistics is more “scientific” and “believable” than “actual” data, and whether the two could be merged.

“Them as Has, Gets”: Power and Health Studies

Discussion of economic concerns and political power differed considerably across the three groups. The facilitator asked all three groups if all communities on the North Shore equally share concern for environmental health in general, and about the effects of the Salem Harbor

Station in particular. There was agreement among participants in the Marblehead and Informed groups that environmental health problems associated with the Salem Harbor Station are worse in Marblehead and Swampscott than in Salem or Lynn due to prevailing wind patterns. The omission of Salem from the Mass DPH cancer study was barely discussed in these groups, except in how it might be related to the residents' lack of political power and overriding economic influences on the city. In the Marblehead group Marilyn acknowledged that the study came about as a result of a mandate by the state legislature. Aaron said, "I know [Salem residents] are very concerned about jobs. Their tax base relies heavily on the power plant.... So there is a lot of support for the power plant in Salem." Indeed, participants in the Salem group also identified support for the power plant in the city, and potential for economic concerns to outweigh health concerns among residents.

Salem group—In the Salem group there was extensive discussion about the economic and political differences between Salem, home of the power plant, and Marblehead across the harbor. In contrast to the Marblehead and Informed groups, participants in the Salem group talked at length about why Salem was not included in the Mass DPH cancer study, implying that it might have to do with wealth, political influence, access to expertise, or economic dependence upon the plant. In response to the question about why Salem was not included in the study, Stephanie responded, "Probably because the folks in Marblehead or Swampscott were screaming more loudly." Caroline immediately followed, "Salem is more blue-collar. Marblehead and Swampscott are more white-collar."

For the most part, participants in the Salem group saw no reason for Marblehead residents to be more concerned about environmental health than Salem residents. When asked if Salem could have had a health study focused on Salem if they wanted, Caroline said, "It would have been a lot harder. A lot harder getting the people together, a lot harder. Wealth helps." Stephanie chimed in, "[T]here is a very divided feeling in this community because people think of the jobs associated with the plant and they also, more importantly, think of the taxes." Stephanie described her conviction that economic dependence on the power plant drives the interests of political leaders in Salem, drawing attention to the fact that it was a Republican Governor who declared his intent to clean up the Salem Harbor Station, "... and we have our Democratic mayor, who you would expect would be more conscious of environmental issues, going and saying, 'Shhh!'" Everyone agreed that the Mayor of Salem was not supportive of the Governor's declaration to regulate pollution at the Salem Harbor Station, implying that even the democratic mayor was swayed by the city's economic dependence on the plant. Outside the Salem group, the strongest comment made to this effect came from Deirdre, a resident of Salem in the Informed group: "I guess the way systems work, it is money and power driven. And usually the people with the money and power have control over the information."

The Salem group was the only group that raised the topic of racial or ethnic and cultural diversity as being important considerations in the conduct of a health study or in the process of communicating study findings. Participants mentioned the importance of being sensitive to people "from different countries who live here and... don't speak the language." Searching for a reason why Salem would also not be the focus of a study, Janet suggested the logic for why low-income communities are often overburdened by environmental hazards may be related to the apparent unwillingness by public health agencies to include them in studies:

[W]hen they are looking for sites to put these things, it is very strategic where they are placed. ...in towns or cities that are more blue-collar. ...people that maybe wouldn't necessarily have a more powerful voice as people in Marblehead do because they have more money. So they have less power and can be exploited.

DISCUSSION

Our findings suggest three distinct yet related concepts that contribute to community perceptions of environmental health, and studies conducted to address community environmental health concerns: tangible evidence, trust, and power. Together they function as a lens through which environment, health and science are viewed. There were key differences between focus groups in how each of these concepts is expressed.

Participants in all three focus groups had difficulty accepting the findings of health studies when scientific results contradicted lay knowledge. The *struggle* to reconcile conflicting types of knowledge, lay and scientific, was most apparent among participants in the Informed and Marblehead groups. Participants in these two groups were inclined to consider the findings of studies that conflicted with their experience, and struggled to make sense of the science. In contrast, participants in the Salem group (the environmental justice communities) relied more readily on their own experience without struggling to reconcile the two types of knowledge. Instead, when the results of science conflicted with their own knowledge, participants were adamant in the accuracy of their own opinions of the study findings based on tangible evidence.

Participants in the Marblehead group mentioned common sense. Rather than draw on their own experience, some Marblehead participants relied on common sense over science. Their reliance on common sense versus scientific knowledge, however, was far less pronounced than the reliance on tangible evidence by the Salem group. Common sense is another form of lay knowledge, as it is rooted in experience and is distinct from methodologically mediated, professional or scientific knowledge, and is a more universally accessible, culturally shared perception (Schutz, 1953). Common sense is by definition representative of a majority perspective. Because people acquire and characterize knowledge differently depending on their context, people living in areas documented to have an unusually high or disproportionate burden of environmental exposures may have a different or *uncommon* perspective that reflects their experience. In their reliance on tangible evidence (personal experience of exposure and health), the Salem group was aware that their experience of environmental health is not universally shared or common. Participants suggested that their experience is not appreciated and even ignored by the agencies responsible for protecting their environmental health. It is argued here that tangible evidence is a specific form of lay knowledge that includes experience of disease and sensory perceptions of exposure and which some people rely on more heavily when interpreting the findings of scientific health studies, but which, like other forms of knowledge, is not monolithic or exclusive.

In the Salem group, mistrust in institutions and government agencies, coupled with a perceived lack of political and economic power, and bolstered the perspective that findings of health studies are strongly tied to the interests of the institutions that sponsor or conduct them. Fischer (2000) suggests that when people lack trust in the source of health knowledge (i.e., a government agency) they question the validity of the knowledge produced. In the Salem group, government agencies and research institutions were regarded as birds of a feather, equally susceptible to the influence of politics and funding. Our findings contribute to a body of literature showing that perceived trustworthiness and social credibility of scientific information is associated with public attitudes about the institutions that provide the information (Bush, Moffatt, & Dunn, 2001; Peres, Moreira, Rodrigues, & Claudio, 2006). In contrast with the Salem group, trust in researchers and agencies was not a prominent theme among residents of the higher income, predominantly white towns of Marblehead or Swampscott who participated in the Marblehead group. Additionally, participants in the Marblehead group suggested more trust in, and access to, their local officials.

In the Marblehead group trust was discussed in terms of the methodological limitations of science: “If you don’t like the methodology, then you can’t trust the result.” Salem participants, however, did not scrutinize the relevance of study methods. Instead they focused on their distrust for the institutions sponsoring and conducting studies, and on the structural forces that contribute to the conditions of their environments. Differences between groups in how trust was discussed are related to differences in perceived political and economic power between the groups.

Participants in the Salem group were of the opinion that societal forces kept their areas (and the people who live there) from being the subject of health studies. They suggested that their economic and political vulnerability led them to doubt that their communities would ever be the focus of a study that resulted in improved health of residents, or would be anything other than inconclusive and otherwise meaningless. In other words, getting a study that would make a difference would require political and economic power they did not have.

Upon reflection, it was not surprising that the Salem group would draw upon tangible evidence more readily, given they are *more likely* to have experienced tangible evidence of environmental degradation and health effects of pollution. After all, Salem and Lynn are among the top twenty towns most burdened by environmental hazards in Massachusetts, and Marblehead and Swampscott are not (Faber & Krieg, 2005). The environmental justice movement has struggled for the voices of people bearing the burden of toxic waste and pollution to be heard by those with the authority and power to effect change. Shifting this power requires the recognition and acceptance of lay knowledge, or specifically tangible evidence, by institutions which predominantly rely on scientific evidence. As is, professional knowledge that meets scientific standards is more likely to be acted on by public agencies than lay knowledge. Residents who are more reliant on lay knowledge than professional knowledge, and who experience tangible evidence of environmental health threats daily, believe that professional institutions work in the interests of more powerful people and communities who share those professionals’ ways of knowing (Tesh, 2000). This perception may have public health implications.

A study of perceptions of air pollution conducted in Birmingham, England, found that physical and social encounters with air pollution were important in shaping perceptions of health, and that when confronted with scientific evidence, “trust and reliance is still strongly placed in people’s own experience” (Bickerstaff & Walker, 2001). Additional studies demonstrate that perception may itself be a variable in the web of disease causality. For example, perception of well-being is a strong indicator of mortality compared with objective measures of health status (Blazer, Sachs-Ericsson, & Hybels, 2005), subjective ratings of neighborhood crime are a stronger predictor of behavior (e.g., walking outside) than actual crime rates (Kawachi & Berkman, 2003), and perceived social status may be a more powerful indicator of health than objective, numeric indicators of social status (e.g., income, employment, education) (Goodman, Huang, Schafer-Kalkhoff, & Adler, 2007). Further, while the differences between groups in our small study cannot be definitively explained, these findings contribute to theories of neighborhood effects on health.

A neighborhood includes the social, physical, biologic and chemical environment; where we live, what we live in, and the social structures, institutions and people with whom we live. A number of epidemiologic studies have identified moderate associations between neighborhood environment and mortality after adjusting for individual income, employment status, access to medical care, smoking, drinking, exercise, body mass index, and social ties (Kawachi & Berkman, 2003). In addition to mortality risk, health outcomes associated with community context when individual attributes and behaviors are taken into account include low birth weight, asthma, injury, and cardiovascular disease. Many community-level predictors of

individual health status are also indicators of socioeconomic inequality, (e.g., racial segregation, concentrated poverty and/or affluence, poor quality housing) (Sampson 2003). However, our findings illustrate that individual variables that define socioeconomic status, including race, are not the determining influence on perceptions of health studies.

The differences in perception of the science between groups are not explained by the race, ethnicity, educational attainment or income levels of participants. All but one of the focus group participants were white or Caucasian, several participants in all groups had graduate academic degrees, and the reported income levels of individuals across groups did not differ greatly. Despite similarities in the individual level attributes of participants across focus groups, differences in perspective between focus groups exhibited evidence of community or contextual level differences that have to do with their city or neighborhood of residence. It may be argued that the differences observed between respondents in each group reflect the situation of the places where they live. This finding extends a growing literature on neighborhood or community effects on health (Kawachi & Berkman, 2003; Popay, Thomas, Williams, Bennett, Gatrell, & Bostock, 2003; Sampson, 2003), particularly as they are associated with health inequalities. The focus group findings add to this literature by suggesting that rootedness in or experience of a particular place has the power to shape individual perceptions of health studies, and conceivably health.

There is still much we do not understand about how people use tangible evidence and how this shapes views about what types of methods and data might be used in health studies. Understanding the dynamics between tangible evidence, trust, and power may help all stakeholders in community health studies better comprehend the potentials and limitations of studies, as well as the hopes that different people, from different locations, place in them.

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Table 1

Focus Group Demographics

Demographics	Salem	Marblehead	Informed
	N=7	N=7	N=8
Gender (Female, Male)	6,1	4,3	6,2
Self-Identified Ethnicity	6 Caucasian 1 Black	6 Caucasian 1 Jewish	8 Caucasian
Age			
18 – 24	1	0	0
25 – 35	0	1	0
36 – 50	3	4	2
51 – 65	2	1	3
Over 65	1	1	3
Education			
High school	2	1	0
College	1	1	2
Graduate	4	5	6
Household Income * (in \$000)			
21–37	2	1	1
38–60	2	2	3
61–100	2	2	2
Over 100	1	1	2
Town of Residence			
Marblehead	0	2	4
Swampscott	0	5	1
Salem	6	0	2
Lynn	1	0	1

* not all participants reported income