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Disentangling the Exposure Experience: The Roles of Community Context and Report-back of Environmental Exposure Data

Crystal Adams¹, Phil Brown¹, Rachel Morello-Frosch², Julia Green Brody³, Ruthann Rudel³, Ami Zota⁴, Sarah Dunagan³, Jessica Tovar⁵, and Sharyle Patton⁶

¹Brown University, Providence, RI, USA

²University of California, Berkeley, CA, USA

³Silent Spring Institute, Newton, MA, USA

⁴University of California, San Francisco, CA, USA

⁵Communities for a Better Environment, Oakland, CA, USA

⁶Commonweal, Bolinas, CA, USA

Abstract

This article examines participants' responses to receiving their results in a study of household exposure to endocrine disrupting compounds and other pollutants. We study how the "exposure experience"—the embodied, personal experience and understanding of chronic exposure to environmental pollutants—is shaped by community context and the report-back process itself. In addition, we investigate an activist, collective form of exposure experience. We analyze themes of expectations and learning, trust, and action. The findings reveal that while participants interpret scientific results to affirm lay knowledge of urban industrial toxics, they also absorb new information regarding other pollutant sources. By linking the public understanding of science literature to the illness and exposure experience concepts, this study unravels the complex relationship between lay experience and lay understanding of science. It also shows that to support policy development and/or social change, community-based participatory research efforts must attend to participants' understanding of science.

Keywords

Environmental health; exposure assessment; public involvement in science; illness experience; health social movements

INTRODUCTION

In an earlier household chemical exposure study that reported individual results to women in the high breast-cancer-incidence region of Cape Cod, MA, we found that lay participants' interpretation of science was multifaceted, and that technical content and the lived experience were intertwined (Altman et al. 2008). Drawing on the illness experience literature, we called this learning process and resulting state of mind the "exposure experience," which is "a new category of embodied experience that is becoming increasingly common as more individuals, communities, and populations learn about chemicals in their bodies and everyday environments" (Altman et al. 2008:419–420). The study resulted in a transformation in participants' conceptions of the sources of environmental exposure and their affect on health. We wondered whether we would find a

different exposure experience in other socioeconomic contexts, particularly in communities with major industrial and transportation emissions sources and substantial political organizing around pollution.

This paper expands the concept of exposure experience in two ways. First, it examines the influence of two dimensions of the exposure experience—the community context and the study’s report-back process—on participants’ perceptions of exposure study results in two communities that differ in their demographic composition and in their history and interaction with sources of toxic contamination. In our two communities of interest, community context involves the community’s history with local industry, the nature of environmental problems in the community, and the role of local advocacy organizations. The report-back process involves the manner in which the research team provides information to the study participants. Unlike most public health exposure studies, this study supports participants’ right-to-know, if they wish, the results of studies in which they take part, regardless of their scientific background or literacy level (Brody et al. 2007; Morello-Frosch et al. 2009).

Second, this paper examines a facet of the exposure experience in which a collective, action-oriented group understanding develops. Here, the collective groups are two sets of community residents tied together by membership in an environmental health organization and/or participation in a research study. Collective exposure experience can also apply to members of a non-geographic community, e.g., people who have or are at risk of getting a disease.

THEORETICAL BACKGROUND

This research aims to expand traditional medical sociology by integrating two literatures less central to medical sociology, health social movements and the public engagement with science, with a traditional medical sociology literature: the illness experience tradition. The illness experience concept has been an established part of mainstream medical sociology for over four decades. To study one variant of the illness experience, what we term the exposure experience, we draw on the health social movements literature, which is housed in medical sociology and in social movements sociology. We also draw on the public engagement with science literature, which includes public understanding of science and health literacy research, and lay-professional collaborations such as community-based participatory research (CBPR).

Illness Experience and the Exposure Experience

Illness experience was originally a formulation that challenged professional dominance approaches (see Freidson 1970; Mishler et al. 1981). The early illness experience literature studied patients’ experiences with illnesses that were well-recognized by the medical community. Over time, the field became interested in the study of illnesses characterized by a host of symptoms that baffled medical experts, such as fibromyalgia, chronic fatigue syndrome, and multiple chemical sensitivity syndrome. While the transition into an illness identity is usually marked by some degree of ambiguity, an uncontested, legitimated diagnosis allows an individual to impose order upon and achieve a sense of control over their illness experience. Scholars (Draucker 1991; Madden and Sim 2006) have shown that the high degree of uncertainty associated with contested illnesses regarding the legitimacy and/or etiology of physical pain makes the illness experience of contested illnesses distinct from that of traditional illnesses. Responding to this uncertainty, sufferers often turn to collective groups, such as electronic forums (Barker 2008) and patient schools (Bulow 2004), for an alternative form of validation. Some laypersons, frustrated with being ignored by the medical community, take the role of researcher into their own hands by becoming

“citizen scientists,” laypersons that are experts in their own subjective illness experience (Brown 1992; Kroll-Smith and Floyd 1997). These sufferers often become socially and politically active in order to increase awareness and/or find answers and solutions to their health problems.

In recent years, the illness experience literature has shifted to focus on the centrality of the body in the direct, lived experience of disease or the risk of getting disease, what is referred to as the embodied illness experience (Freund, Podhurst and McGuire 2002).

Acknowledging the embodied quality of the illness experience is especially important when disease causation and/or recognition is uncertain, which is true of many environmentally-induced diseases (Morello-Frosch et al. 2006).

Drawing on the illness experience literature, particularly contemporary applications that evaluate contested illnesses and disease embodiment, we formulated the exposure experience concept to evaluate the personal, ambiguous experience of living with chronic pollutant exposures. The exposure experience offers a framework for analyzing how scientific understanding and embodied experiences emerge simultaneously. This concept fills a gap in the illness experience literature on the role that science, particularly exposure studies, plays in informing the public about environmental contaminants that are potentially linked to adverse health outcomes. Previously, illness experience was relevant for disease-affected people and groups. The exposure experience concept expands this lens to view communities, and ultimately the whole society, as what we consider “health-threatened.” We use illness experience as an analog to ask, “How do people experience, understand and respond to a concrete physical presence of potentially harmful pollutants?” For those who initiate an exposure study, as well as their larger constituency, the interest in contaminant exposures derives from their felt experience of or concern about disease. Hence, illness experience provides a basis for considering exposure experience as a new variant of illness experience. A variety of exposure experiences can exist within a community. This study investigates the role community context plays in shaping the various exposure experiences of participants of exposure studies. In focusing on community context, we pay particular attention to how community organizations help shape the health frames of the wider community. Research on acute disasters (Edelstein 2004; Vynner 1989) deeply shapes our knowledge of how community context affects the experience of exposures, and this literature informs our understanding of people’s experience of chronic contaminant exposures.

Health Social Movements

Recent applications of collective approaches to the study of illness experience have advanced knowledge in two ways: 1) by unveiling how the sharing of experiences through support groups and virtual communities gives illness experience a public face that often challenges traditional biomedical models; and 2) by researching and theorizing how health social movements (HSMs) challenge and transform the power relations that give rise to disease and alter the lay public’s experience and perception of illness. HSMs can facilitate the transformation of personal troubles into social problems, yielding collective answers that illuminate the environmental determinants of health hazards and that suggest alternative etiologies of diseases.

HSMs are networks comprised of both formal and informal organizations, lay supporters, media, and even government actors that mobilize in response to issues of healthcare policy and politics, medical research and practice, and medical and scientific belief systems. These movements challenge political power, professional authority, and personal and collective identity (McCormick et al. 2003) and they play a central role in all aspects of health care, illness experience, and lay-professional interaction (Brown and Zavestoski 2005; Frickel and

Moore 2006; Moss and Teghtsoonian 2008; Banaszak-Holl et al. 2010). HSMs are especially important for helping people mobilize when there are uncertainties regarding disease causation. The involvement of social movement organizations in our project provided a prior foundation that facilitated people's interest in participating in the exposure study and gave them a vehicle to transform their health concerns into social movement actions.

Public Engagement with Science

One stream of public engagement with science research connects public understanding of science to health literacy. The scholarship on public understanding of science has evolved from an emphasis on the "public deficit" in scientific knowledge to a focus on how laypeople draw on their social as well as their technical experience to interpret scientific findings (Irwin and Wynne 1996). Despite this shift, most public understanding of science scholars have been criticized recently for taking a one-dimensional, paternalistic perspective, where lay knowledge and experience is subordinated to the expertise of scientists. Contemporary scholars are critical of this approach to public engagement, claiming it fails to reestablish the public's trust in science and accusing scientists of being primarily interested in self-promotion rather than a lay-science dialogue (Wynne 2006).

In a vein similar to the deficit models in the public understanding of science tradition, medical and public health practitioners identify health literacy as a factor in health disparities, because poor reading and math skills limit access and understanding of scientific information. *Healthy People 2010* defines health literacy as, "The degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions" (US Department of Health Services 2010). Health literacy techniques, such as the frequently used benchmark that literature be pitched at an early grade level (Rudd et al. 2007), run the risk of legitimizing studies that do not inform participants and communities about research results.

A separate stream of public engagement with science research contends that in order to boost understanding and literacy among both laypersons and scientists, the public must be more deeply involved in science. This includes lay-professional collaborations such as CBPR. For environmental lay-professional collaborations in particular, citizen-science alliances can alter the exposure experience by transforming how individuals view the technical content of science (Brown 2007), the institution of science (Krimsky 2003), and the policymakers that rely on science to make decisions (Corburn 2005). Scientists in various disciplines often fail to acknowledge that the lived experience of chemical exposures can contribute to attempts to resolve scientific uncertainties. But increasingly, laypersons living in contaminated communities draw on a store of first-hand experience and knowledge that is important, relevant, and can challenge scientific expertise (Coburn 2005). Often, they rely on "tangible evidence" of contamination, such as visible soot from a nearby power plant (Scammell et al. 2009).

Our research takes a CBPR approach, in which community residents and/or organizations are involved in all phases of the research process (Minkler and Wallerstein 2003). CBPR involves lay persons in a collaborative, egalitarian fashion, which compels scientists and advocacy organizations to think carefully about whether and how to provide exposure results to individuals. Community participants and organizations inform how report-back is conducted, and thus they take control in shaping their exposure experience. Critics of report-back have understandable concerns about the emotional and psychological stress for participants trying to make sense of data that does not provide a clear picture of health implications or clear guidance on how to reduce exposures (Morello-Frosch et al. 2009). Our team has sought to mitigate the potential stress posed by the scientific uncertainty regarding

the health effects of chemical exposures by integrating results communication with a discussion of individual and collective strategies to decrease exposures.

RESEARCH QUESTIONS

In prior work, we found Cape Cod residents, white and mostly middle income, learned much from an intensive report-back process on exposure data (Altman et al. 2008). We were interested in whether it was possible to do such work in a low-income, largely minority community. Stemming from this, two research questions shape our study: First, when residents are presented with environmental health information that may be uncertain, how does community context shape their exposure experience? In particular, we examine three aspects of the community context that have an influential impact on the exposure experience: expectations and learning, trust, and personal/collective action. Second, how does the report-back process shape the exposure experience, and does it lead to individual or collective action? In particular, we examine the role of participants and non-participant residents in interpreting and acting upon the information they are given about both individual- and community-level results.

DATA AND METHODS

The Northern California Household Exposure Study

The qualitative study described in this paper is part of a larger CBPR project conducted by a multidisciplinary collaborative composed of two academic partners, Brown University and the University of California, Berkeley; Silent Spring Institute, a research institute focused on the environment and women's health, especially breast cancer; and Communities for a Better Environment (CBE), an environmental justice organization in California. The Household Exposure Study (HES) discussed here was based on a similar study conducted by Silent Spring Institute in Cape Cod, MA (Rudel et al. 2003). The current project assessed exposures to pollutants from local emission sources, including industry and transportation, and consumer products (Brody et al. 2009; Rudel et al. 2010).

Study setting—Richmond was selected for the project because of its different emission source profile and demographic make-up from the Cape Cod study site. In addition, it was selected because the city's longstanding struggle with environmental justice issues and its high level of environmental justice activism make it a unique case. The study measured compounds from heavy oil combustion in order to capture the effects of the Chevron Richmond Refinery, one of the nation's largest oil refineries (Chevron 2009a; Chevron 2009b). Richmond is located in Contra Costa County, one of the most industrialized counties in the Western United States (City of Richmond 2010), and its disproportionate burden of major industrial facilities, small area emitters and transportation emission sources has been an ongoing environmental justice concern throughout Richmond's history. During the course of the study, CBE was involved in several court cases against Chevron and the City of Richmond in an effort to ban Chevron's proposed oil refinery expansion. Richmond is a disproportionately minority, working class city. According to the 2000 US Census (2002), the community was 61% Latino (including many monolingual Spanish-speakers), 18% African-American, and 3% Asian-American; 26% of residents had incomes below the federal poverty level (\$17,603 for a family of four), and half had incomes below 200% of the poverty line. Housing is a combination of renter- and owner-occupied units, with modest yards. Contra Costa County has high cancer and respiratory risks due to industrial air toxics (Pastor, Sadd and Morello-Frosch 2007).

In contrast, Bolinas is a predominantly white, middle-class, coastal community twenty miles west of Richmond. Bolinas was added to the study on the recommendation of the project's

community advisory board, which sought a non-industrialized location to compare to Richmond. Bolinas is known for being a reclusive enclave and it has a long history of environmentalism (Brown 2000). According to the 2000 census, the small unincorporated community of 1,246 people was 91% White, 2% African American, 2% Asian, and 5% Latino; the median household income was \$53,188 (US Census 2002). Like Richmond, Bolinas also has an active environmental organization. Commonweal, a nonprofit health and environmental research institute, has its headquarters and a retreat center in Bolinas. Although not a funded partner in this collaborative, Commonweal helped recruit many of the study's participants in Bolinas.

Household Sampling Methods and Results—We recruited 40 participants from nonsmoker homes in the Liberty/Atchison Village in Richmond and 10 in Bolinas. Participants were predominantly middle aged women. Responding to a question that allowed for choice of more than one category, 41% of Richmond participants identified as Hispanic, 54% as White, and 11% selected another race/ethnicity; 38% were interviewed in Spanish. In Bolinas, none identified as Hispanic, 80% identified as White, and 40% selected another race/ethnicity; all Bolinas participants were interviewed in English. In Richmond, 37% had a college education compared to 100% in Bolinas. Further details of our recruitment procedure and participant characteristics are reported elsewhere (Brody et al. 2009). In Bolinas, Commonweal aided the research team in participant recruitment, and in Richmond nearly half of the sample volunteered with CBE.

In 2006, we collected indoor and outdoor air and dust from the homes, documented housing characteristics (such as room size and the presence of rugs and carpets), and interviewed participants about their product use, demographics, and expectations of the study. Samples were analyzed for over 150 chemicals, including pollutants associated with industry and transportation, as well as endocrine disrupting compounds, which are found in consumer products and building materials and are thought to increase the risk of breast cancer and other diseases.

Results showed a greater number and higher concentrations of industrial/transportation pollutants in Richmond compared to Bolinas. In addition, these outdoor pollutants migrated into homes. Levels of vanadium and nickel in Richmond were among the highest in the state, and indicated heavy oil combustion from refining and marine shipping (Brody et al. 2009). In nearly half of Richmond homes, fine particulate matter (PM_{2.5}) levels exceeded California's ambient air quality standard. Chemicals that come from indoor sources, such as consumer products, were abundant in both Richmond and Bolinas homes (Rudel et al. 2010). We found flame retardants (PBDEs) in dust in Richmond and Bolinas at levels higher than the rest of the country and the world, which is likely due to the state's stringent furniture flammability standard (Zota et al. 2008).

Results Report-Back and Follow-Up Interviews

We asked study participants during informed consent for the household sampling if they wanted to receive the results for their home. A year after samples were collected, we contacted the participants who wanted their results to inform them that they would receive a package with their sampling results and to invite them to schedule a home visit with a CBE or Silent Spring Institute staff member to review the materials. Results were mailed or hand delivered to the 95% of study participants who requested them. Results packets consisted of a cover letter (reminding participants about the purpose of the study) and an extensive array of materials, as shown in Table 1.

During a second home visit with participants, team members reviewed study results, answered questions, and provided exposure reduction resources, such as fact sheets on wood

stoves and integrated pest management. Participants were then contacted by phone to schedule a follow-up home interview about their experiences with the study and the report-back process. During this semi-structured follow-up interview, we asked participants to describe their experience participating in the sampling, their understanding of results for their home, their emotional response, and any actions they had considered in response to their results. The sequence of contacts with individual participants throughout the study is shown in Table 2. We conducted follow-up interviews, lasting approximately 1 hour, with 32 participants (64%); 2 participants moved, 5 were unable to schedule interviews, and 9 declined.

In addition, we held community meetings before and after sample collection to give participants and non-participants the opportunity to provide input and learn about the study's results. Overall, our report-back approach was very rich in interaction.

Analysis

Interviews were transcribed, and transcripts were imported into NVivo 8.0, a qualitative data management and analysis program. A coding scheme was created that closely mirrored the post-sampling questionnaire. A member of the research team conducted an initial analysis of the interviews and created a set of preliminary response categories for each question. Then, the team member conducted a more detailed reading of each interview and coded each response into the appropriate category. Response categories were adapted to better fit the interview material. This involved creating new categories, deleting old ones, and merging categories.

In addition to the systematic NVivo coding process, a team member constructed interview summaries for each participant describing overall impressions and detailing themes of expectations and learning, trust, and action. Rather than force a preconceived result on the data, these themes were identified via an inductive analysis of the transcripts. To achieve intercoder reliability, two other members of the team constructed interview summaries for 5 participants and these summaries were compared. The systematic coding and interview summary analytic techniques allowed us to more precisely specify patterns and themes.

Study Limitations

A major limitation of the study is that the sample is not representative of their respective communities' demographic profile. Thus, we cannot determine that the exposure experience we characterize here represents the exposure experience for the entire community, since activists are likely overrepresented among our participants. In addition, residents who attended community meetings but were not participants in the sampling were not systematically interviewed, so our data about them is limited to their public statements in the meetings. Because most of the participants were from Richmond and CBE was a formal partner, we discuss Richmond's findings and community context more than Bolinas'. We feel this is acceptable since the project was initially centered on Richmond and Bolinas was added to the study to put Richmond's findings into context. We lost a greater number of Spanish-speaking participants in the follow-up process (particularly in the interviews after the report-back). Therefore, Spanish-speaking participants' perspectives may be underrepresented in our results. Finally, the study is limited in terms of how scientists' orientations and research methods are affected by citizen-science alliances. While the focus here is on residents' perception of environmental exposures, we have written elsewhere (Morello-Frosch et al. 2009) about how scientists have changed their approaches based on interaction with affected publics.

RESULTS

Community members demonstrated a capacity to understand and grapple with the scientific complexity and uncertainty associated with the results of the HES. Through their involvement in the study, Richmond participants in particular became informed and empowered to discuss and inquire about the implications of their results. Richmond and Bolinas participants alike developed a unique exposure experience based on what they learned about the chemicals discovered in their indoor and outdoor environments. While participants came to the study with a prior form of exposure experience, because of their general awareness of and experience with toxic exposure, the HES added enormous scientific data that reshaped and deepened their exposure experience. They developed a deeper awareness of how their neighborhoods and municipalities were affected by cumulative exposure to many chemicals. Armed with this new knowledge and aided by community-based organizations, they planned and sometimes implemented many personal and collective actions to reduce future exposures, and in Richmond they took legal and political action to address exposures from outdoor industrial emission sources.

To examine research question 1, we detail three elements of the community context that played an influential role in shaping the participants' exposure experience: participants' expectations of and learning from results; trust in government, business, and community-based organizations; and personal and collective actions. We then discuss the findings for research question 2.

The Effect of Community Context on the Exposure Experience

Expectations and Learning, as Affected by Community Context—We separately consider people's responses to exposures from industrial and transportation emissions (outdoor exposures) and exposures from consumer products and building materials (indoor exposures), because 1) our past research shows that people conceptualize these sources very differently, and 2) the two communities differ markedly in terms of exposures from industrial and transportation sources.

Prior to the sampling, Bolinas participants reported expecting few or low levels of indoor and outdoor chemicals. They expected “a clean bill of health” and to pass with “flying colors,” given Bolinas' location on the coast, its lack of industry, and its reputation for having environmentally conscious residents. In contrast to Bolinas' initial optimistic health frame, Richmond residents expected that pollution coming from industry, traffic, the marine terminal, and the local railroad would have a negative impact on their household environment, though some nevertheless held out hope that their results would not be bad. The quotes below reveal the tension Richmond participants experienced between their expectations, their hopes, and their actual interpretation of their results:

I wish I could say... I wasn't surprised; because I know that I'm living with a chemical factory in my back yard and Chevron in my front yard, and I know that I should be high, but still ... (Richmond participant).

I mean, not when I think of it rationally but I think from my denial. Like, I just want to believe it's ok. But when I think rationally about our situation I'd have to say, “no, it's not surprising.” But if I think on a feeling level, yeah. On a feeling level I was surprised (Richmond participant).

Upon learning their indoor results, both Richmond and Bolinas participants' health frames toward their indoor environment changed. Both sets of residents thought of their homes as a safe haven from the health effects of chemicals, so they were similarly surprised that pollutants from everyday consumer products and from pesticides banned years ago were

found inside. In Bolinas, there is a general notion that a healthy environment can be maintained by avoiding consumer products with dangerous chemicals. In Richmond, the focus is on “shelter-in-place,” the county public health agencies’ instructions to seal doors and windows and remain inside if there is a fire or leak from the refinery. One Richmond resident felt that “shelter-in-place” had a different meaning for her after she learned the study results; she no longer believed her home served as a haven from dangerous pollutants. The shock experienced by participants from both communities when they learned that their indoor environment was contaminated in spite of their diligence shows they had a prior belief that chemicals can and should be prevented from toxic trespass. Upon reflection, participants learned that even in a community without industry, the home is not a haven but is instead another source of potential disease. Participants were surprised that Bolinas’ indoor exposures were closer to Richmond’s than they expected. As one Richmond participant said, “It’s interesting how the indoor [pollution] is higher in both of the communities [than outdoor pollution]... I mean they’re very starkly different. Polar opposite-type of environments.” A Bolinas participant noted, “I’m sort of revising my thinking about indoor pollution, because I tend to think of Richmond as having a lot of outdoor pollution because of the oil refineries.” This surprise led people to say that consumer product results were more powerful than industrial/transportation results in changing their minds about chemical hazards.

Bolinas and Richmond participants alike indicated no change in their views about the role of chemicals in disease and illness. This lack of change was due to their previous awareness of the potential dangers of toxics. Most participants who reported a change added that they already suspected that chemicals in their environment were associated with health issues, and that the results validated these suspicions. Asthma and cancer came up most commonly, with allergies also being noted. One resident noted that “it affirmed what I kind of sort of knew, but nonetheless it scared me because I’ve had a serious asthma problem for years.” Another commented,

There are a lot of people in this community, a lot of people with cancer. A lot of people with asthma, the children have a high incidence of asthma here. You know on my block there are, right here almost within a stone’s throw, there are 6 people with cancer who either died or are going to and since then one other one has been diagnosed. And he’s literally within a stone’s throw of my house and he’s not yet 50 (Richmond participant).

For both communities, people dealt with their initial shock and/or surprise at their results by reasoning it is better to know than be ignorant. This helped ease their anxieties. A Richmond participant was at first “stunned” but then realized every place she ever lived probably “had a lot of toxic stuff” and the only difference between her situation prior to receiving her results and her current state is that, before the study, she “just didn’t know about it.” Viewing the situation this way and speaking to a research team member in the follow-up process helped her alleviate her distress. Others also noted that the researcher conducting the second home visit helped them manage negative feelings:

She sort of put me at ease in a way that these are chemicals in the environment and some of them persist for many years and even if I did clean better they would still be in the air. So, you know, it’s just helped me understand the reality of the environment I live in (Richmond participant).

A participant whose home had some of the highest contaminant levels in the study was “reassured” that “somebody was investigating it and somebody is doing a study to see what it was.”

Overall, people viewed their results through a broad lens. Although most people did not remember many specific chemicals, when they reviewed their results packet during the followup interviews, they often referenced chemical classes, such as pesticides, flame retardants, and phthalates. This is likely because the research team discussed chemical classes more than individual chemicals, since that made the data more accessible and there were many similarities within chemical classes. Compared to Bolinas participants, Richmond participants focused more on industrial/transportation results, likely because of CBE's high profile lawsuits against Chevron that were going on at the time of the study.

When participants were asked to evaluate graphs comparing Richmond's and Bolinas' fine particulate matter levels, most seemed to compare the results observed in the study with their perception of the two communities. Consider the following response from a Bolinas participant:

I make a lot of assumptions about Richmond.... There are millions of cars, there's factories, there's petroleum plants, there's shipping... you know, tight living conditions... so I would assume that generally there would be more problems. Bolinas is not a very dense population and there is one person per half acre or something (Bolinas participant).

Participants in both communities said that Richmond's results for outdoor pollutants were worse than Bolinas'. The research team hypothesized that Richmond would have greater pollution from industrial/transportation sources, a hypothesis matched by general public belief and confirmed by the data.

Trust, as Affected by Community Context—The results shaped Bolinas and Richmond participants' exposure experience by reinforcing prior levels of trust towards different parties. All participants expressed low levels of trust in industry and government officials and high levels of trust toward CBE and Commonwealth, which in turn influenced how they interpreted their results. In Bolinas, distrust of industry reflects the town's reclusive culture; in Richmond, distrust stemmed from the perception that local industry is unwilling to cut emissions. Both Richmond and Bolinas communities referenced industry in terms of blame and accountability. Some participants responded in a general fashion that industry should be responsive to public needs, while others outlined specific actions industry should take. Distrust toward industry was particularly pronounced among the Richmond participants, who felt Chevron and other local industrial facilities that continually resist community demands for safer production practices were largely to blame for their community's pollution. As one participant recounted,

Participant: If you got asthma and ... you going outside ...you will smell it... maybe they have disguised it in some way which we see the, what do you call those?

Researcher: The flaring? Are you talking about the flaring?

Participant: When...yeah...we see the smoke coming out of there and they swear up and down that that's not no flame that's at the bottom of the smoke. They say it's steam that's coming out of the top...at the top of that thing. And I'm not stupid! I know that's not steam! That's flame! (Richmond participant)

When one Richmond participant was asked if she believed her results were high compared to government guidelines, she expressed her suspicion that government and industry work together against the best interests of the community, saying, "some of them [the results] were under the government guidelines. I think the government works with industry so that the guidelines are really high." That is, she felt officially "acceptable" exposure levels were too high to protect health. While other participants seemed to find some relief in the fact that

their results were below government guidelines, most felt that government is not doing enough to regulate industry and is shirking its responsibilities; for example, one participant noted, “if the government were really responsible it would not be hiding information from us or not taking us seriously, which is the current way they seem to operate.” Another Richmond resident commented, “The US government thinks you have to have bodies all over the street before you can outlaw something.” Beyond that general critique, Richmond residents such as this one had clear notions of the class nature of government action:

I think it’s a matter of class...of the people who have more money. The government pays more attention to those people and contaminates less in that area, because we are poor and our community is from a more humble class (Richmond participant).

Respondents did not believe industry would adopt an ethic of public responsibility on its own and thus felt the only way for industry to become environmentally responsible is to force compliance through government regulation and/or legislation. Richmond residents frequently mentioned the Chevron refinery, while Bolinas participants were less likely to talk about manufacturing practice in general, and instead placed the burden on consumers to stop purchasing suspect chemical products so that companies will stop making them.

While the types of environmental regulation supported by Bolinas and Richmond participants can be described as being upstream in scope, the approaches supported by each community were nonetheless different. Bolinas participants were more likely to support the regulation of chemicals, such as a ban on bisphenol A (a plasticizer that is being phased out or regulated by certain companies and jurisdictions, due to endocrine effects). Commonwealth has devoted much effort to informing the community of the dangers of some ingredients in cosmetics and plastics. Conversely, while some Richmond participants also supported bans on chemicals, they were more likely to recommend increased limitations on industrial activities. The two quotes below from Bolinas and Richmond residents reflect this contrast. The Bolinas participant was concerned with polybrominated diphenyl ethers (PBDEs), a class of flame retardant chemicals used in furniture, electronics and other products which were found in high levels in our study (Brody et al. 2009), while the Richmond resident emphasized industrial pollution:

Bolinas participant: Uh, well I guess being specific I’d like to see a ban on bisphenol A in products. And the whole PBDE thing, which I think is a little complicated because the politics around... fires and stuff in California... But I would like to see that people don’t have to ... have their pillows doused in something toxic if they don’t want it to be.

Richmond participant: I would like to see an increase in about a factor of a hundred in the governance interference in the manufacturing process. We are at an absolute low point in governmental regulation. We are so far from what the government should be doing.

Across communities, residents acknowledged that neither government nor industry had proven trustworthy. Hence, they sought government intervention while recognizing that neither business nor government would accept responsibility without public pressure. For most people, this meant grassroots community activism to influence legislators to pass more stringent environmental legislation. Others suggested they needed to directly “hit the pocketbook” of negligent corporations by refusing to purchase products containing hazardous chemicals. For both government- and industry-directed strategies, participants noted the potential for community-level activism to elicit change. This response was likely due to CBE’s and Commonwealth’s prominence in their communities. The quote below is a

typical assessment of CBE and reflects this participant's view of CBE's influence on her own personal behavior:

Well, first of all, CBE is connected to the community anyway, and particularly since the study immersed us more into the community. I think I can say pretty confidently that CBE will continue to try to represent the community, serve the community, and incorporate it into the larger picture of educating the public and making policy change for the benefit of those communities that are most affected by a lot of this pollution (Richmond participant).

Action, as Affected by Community Context—Residents of both communities viewed their involvement in the Northern California HES as a gateway to either personal or political action. They did not expect the research team to act for them, but rather wanted to be empowered to act on their own, as shown in this response:

And that's what I would want from this study, is give me something I can do about it. Don't just give me information that tells me I have problems....Because that's frustrating, you know? But I'm proactive enough that I'll say, "Ok, I have this information now it's up to me to do something. It's not enough for you to do it for me but just to give me some options of what I can do to change it (Bollinas participant).

There was a general interest in leveraging the results to pressure government officials to undertake more stringent regulation of toxics. This was no surprise, given that over half of participants had been involved at some point in their life in some form of activism. For all participants, non-activists, former activists and current activists alike, the study motivated them to become more active or continue to be active. However, while both Bollinas and Richmond residents referenced individual-, community-, state-, national-, and global-level actions, Richmond residents were more likely to discuss their desire to become politically active at the community-level. This was no doubt due to the community's concerns over the Chevron expansion. For many, being active meant speaking publicly at city hearings or writing to the Richmond Planning Commission urging them to reject Chevron's request for permits to expand refinery production. Such political activism was new for this Richmond participant:

I'm not very active, but I forced myself to go to the Chevron rally and march...I was so cold! And then I had to walk all the way home. It seemed like a worthwhile thing to do. I felt motivated to do that (Richmond participant).

When asked what she thought about the sampling results for her home, one participant remarked,

Yes. At first I was thinking, "God, I wish I didn't know all this." But the more I think about it the, more I understand it the more I feel like it helps me to, uh...I mean like...to be more focused in my battle against Chevron and to try to do whatever I can to mitigate or alleviate the toxins that are in my environment... if you don't know the information then you have an excuse for not being active. But if you know the information then you can't not participate in trying to make change (Richmond participant).

Many questions posed by participants to the researchers about their results were practical in nature, centering on how they could use their results to make changes in their own life. Bollinas participants were slightly more likely to discuss personal changes to reduce exposure. However, all participants wanted to know how to reduce chemical levels, and they talked extensively about the personal changes they already made or planned on making in their home to reduce indoor chemical exposures. The most common changes included

switching to environmentally-friendly products, reducing or eliminating pesticide use, increasing ventilation, and introducing air filters. When we asked participants what they would share with others regarding their learning experience in the study, people replied that they would provide advice on the importance of maintaining a clean environment, as this person pointed out:

No matter how hard we try there is always something which is kind of a downer response, but...you know it just means that we have to really be continually vigilant even though we think that we're doing a pretty darn good job, you know. There's always something more we can do... (Bolinas participant)

Participants in both locations were also concerned with ways to leverage the results to elicit change in their community and beyond. Most community-level action focused on outdoor contaminants. One participant expressed her relationship to the study in this way: “[I want to know] ways we could protect ourselves, ...political action we can take. ...action so we can be in the solution.” This response may be due to the presence of CBE and Commonweal, which encouraged and served as an outlet for environmental activism and shaped residents’ exposure experience. Participants mentioned a strikingly wide variety of local-, state-, and national-level actions they would like to engage in, such as writing to the city council, speaking at hearings, and supporting the passage of regulation, among others.

The Effect of the Report-back Process on the Exposure Experience

In this section, we address the second research question: how does the report-back process shape the exposure experience, and does it lead to action? Our report-back process included multiple conversations with participants and non-participants that took place over a two-year period. In addition, we held separate presentations in Richmond and Bolinas to present the aggregate results of the study. These public meetings gave people the opportunity to analyze the data and exchange opinions and ideas for action. This combination of individual and community report-back involved people in a deeper and more collaborative way than is typical in community exposure studies. As a result, it shaped a new awareness among participants that we find encapsulated in the exposure experience.

Participants in Richmond and Bolinas appeared eager to learn from the study in part because they felt the community was the focal point of the exposure study. When asked why they believed the collaborative was conducting the study, the participants replied, “to help or protect the community” or “to increase knowledge” on the part of both scientists and the society at large regarding the dangers to health of toxics. Given the high rates of activism in our sample, it is not surprising that people considered themselves *participants* in the study—and felt they were playing a crucial role in contributing to increased scientific understanding by being involved—rather than *subjects* in a research program. The language participants used when referring to the project reflects this participatory sentiment, such as when some respondents alternated between referring to the study team in first and second person. For example, one participant stated, “*we’re* doing something, you know, that *you’re* doing something really important about it” (emphasis added). One Richmond participant summarized this dominant opinion in this way: “The point is, when we know what chemicals are in *our* communities, *we* need to regulate those chemicals out of our community. It’s not just an intellectual exercise for graduate students in science.”

While participants’ trust in the research team was enhanced by the team’s affiliations with local environmental organizations, high levels of trust in the research team also came from how the study was conducted. During the report-back interview almost all respondents reported having a positive experience with the sample collection, initial interview, and report-back phases of the study. The study participants were pleased that the research team was competent, friendly, and cared enough to make a visit to talk to participants about their

results, offer suggestions on how to improve their indoor and outdoor environments, and respond to requests for information on exposure reduction strategies. Some respondents noted they would not have understood the results without discussing their results packet with the research team. Almost all participants felt the results format, in conjunction with the report-back conversation, was useful; however, some felt the terminology did not speak to their experience, such as one participant who said, “The terminology, here, much of it doesn’t mean anything. The phthalates—you understand it, I don’t. . . . I need to receive the facts in my ordinary terminology that I would understand that would mean more to me.”

Initially, participants in both communities expected clear-cut answers from the research team. Most felt the study would lead them to a clearer understanding of the role of toxics in their environment, and when researchers informed them that little is known about the health effects of most chemicals, the participants, over the course of the study, began to realize that science does not have all the answers. This quote from a Bolinas participant was a typical response to our question about the personal implications of the study:

So you just kind of have a different relationship about how you’ve led your life and what happens. And just knowing that I will never know. The chances are that I will never know whether this chemical actually did this (Bolinas participant).

When asked what additional feedback they would like from the study, respondents mentioned they were interested in additional follow-up studies, further analyses of the current study, or additional community interventions. They also wanted future monitoring done in their community. These responses suggest they found the study interesting and beneficial and wanted to continue to be involved in studies like the Northern California HES. Most participants appreciated the study team and how it conducted the report-back process:

I liked the fact that CBE and Silent Spring care. And they’re very involved. Having the community meetings, especially out here in Atchison Village, it really shows that they do care about the air quality here and the people here. And the information...having the scientists come over and talk and explain things—it’s very enlightening (Richmond participant).

I appreciate that you and your colleagues do this work. You know, it’s like we’re not being ignored (Richmond participant).

This confirms that researchers can effectively disseminate scientific findings to low-income, less-educated communities in ways that enable them to take individual or collective action; it also demonstrates that community organizations can aid researchers in translating exposure study results to communities.

Richmond residents expressed ownership of the HES at community meetings and public hearings and made suggestions for how to use this data for their needs. People put forth research questions for future research, such as studying Vallejo, CA, which has demographics similar to Richmond but has a power plant instead of a refinery as the main polluter. One participant linked the data to another important issue, climate change, suggesting that the community could argue that refinery expansion would violate California’s climate change laws that restrict greenhouse gas emissions.

Overall, residents and participants at the public meetings were very aware of cumulative impact. This perspective, which is growing in acceptance by regulatory scientists, activists, and academic researchers, holds that the totality of environmental burdens must be taken into account when considering siting or expansion of a facility. Indeed, cumulative impact became the legal basis for the lawsuits against Chevron and the City of Richmond that ultimately stalled the refinery expansion.

DISCUSSION

The exposure experience concept draws our attention to how individuals understand, assess and respond to the knowledge that chemicals invade their bodies and personal environments. We found participants in a low-income, largely minority community were as capable as the more-educated Bolinas and Cape Cod residents of learning from an intensive report-back study on household air and dust exposure. All participants were capable of understanding scientific ideas that health literacy scholars typically consider beyond their reach, such as the notion of cumulative exposure. Through a high level of engagement with the local community, the research team was able to understand participants' needs and experiences in order to anticipate community responses to exposure data and better shape the way results were communicated. As a result of this personal and in-depth attention, participants were motivated to learn the meaning and implications of the chemicals found in their homes and community. The design of the study played a key role in motivating people to act individually and collectively on new data that they believed had been gathered in their interest.

Implications: Lay Understanding of Science

Our CBPR approach to lay involvement in science was successful—in terms of educating the community, facilitating community activism to achieve policy gains, and communicating uncertain scientific findings—for several reasons. First, the study team established trust in all stages of research, from the preparatory stage to the reporting of results. When people lack trust in the source of health knowledge, they question the validity of the health knowledge produced (Fischer 2000). The trust participants had in the research team is in part due to the team's attentiveness to the needs of the community, which mirrored the attentiveness of CBE and Commonweal, who are highly trusted in Richmond and Bolinas. Government and industry can overcome a history of community distrust in a similar way, by building linkages to trusted local bodies such as community organizations, and by eliciting input from locals about the role of scientific information in the decision-making process.

Second, the study embedded the research design and results into the participants' community context. The frequent feedback from communities helped researchers to better understand what participants wanted from the study, and to anticipate how participants' local context would likely influence their understanding. This intensive, iterative interaction allowed the team to adjust and align its methods to suit the community's needs. This made the results more applicable to the participants' lived experience. For some participants, the study provided an entrée into a discussion of the potential sources of the most common chemicals found in their community.

Third, the report-back discussion played an important role in motivating participants to consider personal and collective strategies to reduce toxics in their environment. The participants' responses to their indoor findings show that they experienced conceptual shifts that opened up awareness of toxic trespass into the home. This led them to, in the report-back conversation, brainstorm ways to mitigate the harmful health effects of toxics in the home by reducing exposure. However, the report-back conversation revealed that Richmond participants held a different exposure experience when it came to their outdoor results. CBE's history of organizing shaped a "collective exposure experience" because they alerted their members and the wider community, about health hazards related to toxics. They made the health frame the primary focus of attention. Thus, the type of collective activities Richmond participants expressed interest in centered on efforts to block Chevron's refinery expansion and decrease industrial emissions. The research team aided these community members by preparing materials that residents used in their testimony in public meetings, which helped the community win the lawsuits. CBE also launched a health survey that

covered 722 people in our two study neighborhoods and two additional Richmond neighborhoods.

Finally, the research team did not put on an expert façade that was held to be the last word. Rather, the team helped participants come to terms with the scientific uncertainties associated with their results. For example, when researchers did not have answers to a question posed by participants, the research team informed participants that science is constantly in flux, can be contested and does not always yield simple answers. From our analysis of report-back sessions and public meetings, we conclude that toward the conclusion of the study, participants showed a deeper understanding of the enduring scientific uncertainty surrounding toxics. Critics of report-back studies claim that reporting back exposure information, especially when the health implications of many contaminants remain uncertain, will impose undue distress. Our findings suggest that although reporting back individual results at times produced an initial degree of emotional discomfort, study participants devised strategies to mitigate negative emotions. Our protocol of providing home visits to assist participants in interpreting report-back materials and linking results to individual and collective action helped participants understand and make plans to act upon new knowledge regarding contaminated communities and homes. Thus, instead of underestimating lay capacity to grapple with uncertainty, researchers interested in public engagement should be aware that lay empowerment can emerge from an awareness of the limits of science.

Our approach differed from traditional health literacy approaches in terms of the format and content of communication. Regarding format, the team drew on CBE's and Commonwealth's knowledge of the styles and language that help communities better understand new information. The team's presentation format used the communication styles that these community organizations have had success with over the years. Report-back included detailed graphs that visually and intuitively displayed results. Regarding content, this research deviates from typical risk communication strategies used by government agencies and research scientists that focus on participants' specific grasp of data on individual contaminants. That approach is appropriate when results convey a simple, actionable health message that needs to be specifically recalled (e.g., "pregnant women should avoid certain fish due to high mercury levels"). In this study, however, the important scientific and public health messages are broader; for example, outdoor pollution from the refinery penetrates indoors in Richmond, past use of pesticides leaves persistent residues that can endure for decades, and consumer products result in air contamination. Our findings show that people gained an awareness of these broader, more complex health messages.

Implications: Exposure Experience as a Type of Illness Experience

Traditional illness experience deals with illnesses that people *already* have. Exposure experience incorporates illnesses, either contested or uncontested, that people *might get*. It is influenced by people's awareness of disease prevalence in their area (e.g., urban asthma), their collective exposure experience (e.g., women exposed to DDT as pre-teens), or their knowledge about the prevalence and types of diseases and conditions potentially related to increasing levels of endocrine disruptors and other pollutants (e.g., breast cancer or reproductive problems). In addition, the exposure experience incorporates existing illnesses that people suspect have environmental causes, but which traditional epidemiology often fails to understand. Thus, the exposure experience has a less concrete relationship with illness, yet it is nonetheless a real phenomenon among people who become aware of toxics in their environment.

In our study, the participants' exposure experience was intimately tied to their community in a place-based fashion. Participants initially interpreted the study results so that the results

were in accordance with their community's view of the harmful effects of toxics on health and their understanding of the local sources of harmful exposures, and they expanded their understanding in ways they did not anticipate. Participants responded to their altered understanding of the toxics in their environment by using the community as a venue for action.

On a community-level, some remarked that the study motivated them to become more active in their community organizations to make their environment less contaminated. On an individual-level, the study encouraged participants to become more diligent about the products they use and the items they bring into the home. A key finding from our original exposure study on Cape Cod was confirmed in Richmond and Bolinas: people were likely to expect contaminants to come primarily from large industrial sources, and they were surprised at the extent of contamination from personal care and household products. As awareness about the prevalence of chemicals from home products increases, toxics regulation will shift to focus on chemicals that come from everyday products in addition to industrial sources. Whether studies are conducted by government agencies, academics, or advocacy groups, policy implications are nearly always present. Hence, activists have used exposure studies to pressure regulatory agencies for more corporate responsibility and government regulation. Their intensely personal exposure experience shapes these actions, aided by democratic principles embodied in the right-to-know about the pollutants in their homes and bodies.

Using a CBPR approach, this project developed a report-back method that helped shape—as well as reflect—the exposure experience of the two locales. By reporting individual results and conducting an in-depth interview that examined participants' understanding and use of the data, we examined the individual exposure experience. By reporting collective results in community presentations, we gained insight into the collective exposure experience. While this is time-consuming, the implication of this work is that individual- and community-level report-back is necessary when researchers aim for democratic participation, community capacity-building, good science, and effective advocacy. In the case of the HES, the exposure experience was a fluid experience that went from surprise to sense-making to action. We were able to grasp that temporal shift because we had so many points of intervention and contact. We expect that the exposure experience is fluid for other types of community contexts as well. Thus, it is imperative to study the way in which the exposure experience unfolds using longitudinal methods. In our own study, we wonder whether the changes in motivations and behaviors to reduce exposure will be durable.

Future studies should initiate and investigate the influence of other forms of report-back on the exposure experience and clarify how the broader social context plays a role in developing the exposure experience and one of its central elements: lay scientific understanding. Shifts in societal perceptions of the health implications of exposure will challenge medical sociologists to revise theories to account for the exposure experience of individuals and communities. As exposure studies become more common, the exposure experience, at both the individual- and collective-level, will become more salient, and will take its place as a type of illness experience. Lessons learned here are applicable to the many unexplained, multi-symptom diseases, to the alarming increase in the prevalence of many uncontested diseases, and to the increasing evidence of environmental causes of many common diseases. Lastly, because the exposure experience can achieve strength in social movement activity, our approach offers new directions for the study of HSMs as a key part of medical sociology.

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TABLE 1**Contents of Results Packet Provided to Participants in the Northern California Household Exposure Study**

Cover letter
One-page narrative summary of key results and exposure reduction implications for the participant's home
One-page guide to reading the graphs
Graphs showing chemical concentrations in the participant's home compared with other homes in the study and Environmental Protection Agency (EPA) health guidelines, where available
Table of information on potential sources of each chemical in the study
Graph of key community results: comparing particulate matter (PM _{2.5}) in Richmond and Bolinas
One-page summary of study goals, methods and contact information for the study team
Summary of potential sources and health effects of chemical classes in the study

TABLE 2

Participant Contacts in the Northern California Household Exposure Study, 2004–2009.

	Number of Participants		
	Richmond	Bolinas	Total
First Home Visit	40	10	50
<ul style="list-style-type: none"> • Informed consent • Air and dust samples collected • Participants interviewed about product use, household characteristics, study expectations, and experience with activism • Participants offered option to receive individual sampling results 			
Results packets delivered (mail or hand-delivered)	36	10	46
Second Home Visit: Results Report-back	32	9	41
<ul style="list-style-type: none"> • Team member reviewed results packet and answered questions • Exposure reduction information provided 			
Third Home Visit: Follow-up interviews	24	8	32
<ul style="list-style-type: none"> • Second informed consent • Participants interviewed about report-back process and experience participating in the study 			