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Community First Communication: Reversing Information Disparities to Achieve Environmental Justice

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Abstract

We address how information developed and effectively communicated through community based participatory research (CBPR) can reverse long-standing information disparities, empower a community, and be an agent for sustained change. Substantial information and power disparities existed between the polluted community and both the pollution industry and governmental regulators. An environmental justice partnership between a local community organization, physicians, and university performed CBPR and then developed a novel communication strategy to address a series of information disparities around a local water pollution issue. The community established a set of principles to govern the communication of results as soon as they were determined to be scientifically valid, including informing study participants and the community before other interested parties. CBPR results combined with a community-first communication strategy reversed the preexisting information disparities. The novel communication flow reversed the preferential information flow to industry and government associated with the usual scientific publication process. The community was empowered, and industry and government agencies responded positively to study recommendations. The CBPR results together with community first communication led to adoption of both community-wide and individual solutions and provided powerful motivation for behavioral change by industry and residents.

Introduction

Investigations into human health effects from industrial pollution are often driven and/or funded by industry and government, so that both the results and recommendations can be perceived by communities as reflecting the interests of those parties. The customary dissemination of research results first through scientific publication also serves to release findings to the scientific, industry and regulatory communities ahead of the directly affected public. This preferential information flow to industry and government stakeholders can accentuate their unequal power balance with the community.

CBPR, a collaborative approach to research that combines methods of inquiry with community capacity-building strategies to bridge the gaps between knowledge and community practices to improve health,[1] could help address the disparities and power imbalances faced by communities. CBPR has potential to build greater trust and respect between researchers and communities.[2] However although CBPR should help address inequalities among the interested parties, there has been little work on the development of

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improved models to communicate research results to communities in ways that help redress the power inequalities consequent on the information flow. In this paper we describe the successful implementation of a community-first strategy to communicate research results that embodies the principles of CBPR and demonstrably assisted in reducing or reversing information inequalities. We suggest that this model may be more broadly applicable in community research and might be a powerful tool to achieve environmental justice.

Background of Information Disparities

During 2001 and 2002 it became apparent that the community around Little Hocking, Ohio, might be affected by water and air pollution with the chemical perfluorooctanoate (PFOA, known locally as C8). Increasing amounts of PFOA were detected in water of the Little Hocking Water Association (LHWA), levels considerably higher than previously reported in any public water supply. PFOA was used as a surface active agent in the manufacture of Teflon at a nearby industrial facility. Although there is not yet consensus about the toxic effects of PFOA, there are reasons to be prudent in reducing exposure to this chemical. In toxicology testing in experimental animals PFOA has been shown to delay the development of young animals. Rodents fed PFOA develop cancers of the liver, pancreas in testis, although it is believed that PFOA would not work the same way in humans. In sufficient amounts PFOA is toxic to rodents and the earliest effects are damage to the liver. Studies of people who work with PFOA have shown inconsistent results to date, but a positive association between PFOA and serum cholesterol levels has been reported.[3] PFOA is persistent in the environment and in humans, where it had a half life of several years, so that significant accumulation was possible in residents drinking the polluted water. The community became increasingly concerned, not only because of escalating levels in the drinking water, but also by a series of announcements about potential health effects from PFOA, described below.

The interests of a small Appalachian rural community, and a rural water association serving less than 5000 householders, were potentially pitted against those of industry and powerful regulatory agencies. Although the community appeared poised to bear the brunt of whatever effects the chemical pollution may have, it faced the information disparities and sense of powerlessness compared with both industry and government regulators, described by Gaventa.[4] PFOA producers and major industrial users had access to information on the potential toxic effects of PFOA, since almost all readily identifiable published research on whole animal or human toxicity had been industry-sponsored or authored by groups that included employees of PFOA manufacturers or users. The local industrial facility had information on the health of employees exposed to PFOA and according to the local newspaper had previously performed some studies of workers.[5] The facility also had information on potential local environmental contamination, including PFOA in water that had not been disclosed to the community or authorities.[6] The industrial facility controlled the use and potential release of the facility, particularly as PFOA was an ‘unregulated” chemical, and thus not subject to strict standards under national environmental laws such as the Clean Air Act, the Clean Water Act and others.

There were also information and power disparities between regulators and the community. The polluting plant was located in and regulated by West Virginia, whereas the most affected community was across the state border in Ohio. A series of events led the community to perceive that its interests were secondary with this regulator. In 1991 the DuPont Company had established an internal Community Exposure Guideline for PFOA of 1 ppb in water.[7] After detection of PFOA in LHWA well water at levels above this, a Consent Order between U.S. EPA and DuPont cited 14 ppb as the interim “action level”. Subsequently the West Virginia Department of Environmental Protection convened a C-8

Assessment of Toxicity (CATT) Team, which included members who had associations with PFOA-producing or -user companies but no representatives from affected communities. CATT determined that the "safe level" of PFOA in water was now 150 ppb.[8] Interestingly water samples taken from borings in the LHWA well field in August 2002 found PFOA levels up to 78 ppb.[9] Although other explanations may be possible: from the community's perspective, "safe levels" appeared to escalate so that they would always be higher than the highest PFOA levels found in their water. In any case the CATT findings were severely and publicly criticized by the Environmental Working Group, an advocacy organization. A local newspaper poll found that 72 % of residents did not feel safer after the CATT report and that 68% were 'still concerned' or "remain very worried".[10] Not only did the community lack political power to influence business or government[11], especially government located in another state, but it was also disadvantaged by a lack of technical capacity to generate information independent of industry or regulators. For example in 2001, citing commercial relationships, a leading analytic laboratory for PFOA rebuffed efforts by the LHWA to independently test PFOA levels in the water it supplied customers.[12] The LHWA, a rural water association with limited resources, was ill-equipped to deal with the complexity of gathering data, monitoring and making detailed submissions on this chemical.[4] The community of residents of Washington and a small part of Athens counties, both in Appalachia, met the federal environmental justice definition[13] with respect to income. In 1999 the per capita income for Washington County was 78%, and the per-capita market income was 75% of the US average.[14] Moreover Appalachia is a region where federal policies may have sanctioned environmental injustice.[15,16] Those with private well-water supplies may have been even more disadvantaged as they had no means for organized input into decisions concerning PFOA.

Subsequent scientific and policy decisions around PFOA increased community concern although not its influence. For example, the American Conference of Governmental Industrial Hygienists (ACGIH) classified PFOA in Group A3.[17] This classification assessed the unregulated chemical PFOA as a confirmed animal carcinogen with unknown relevance to humans, sharing this classification with regulated chemicals such as chlordane, DDT, heptachlor, and others. 3M Company announced that it would cease the production of PFOA, and subsequently sent a TSCA 8(E) SUBSTANTIAL RISK NOTICE to the U.S. EPA that cited potential reproductive and developmental hazards.[18] USEPA then undertook a policy review that eventually led to PFOA's classification as a potential human carcinogen. The community had no direct input into these assessments. The many information and power disparities accentuated the lack of mutual trust between the community and other stakeholders; particularly with industry and the West Virginia Department of Environmental Protection. Major information and power disparities between the community and industry and regulators are listed in Table I.

The Environmental Justice Research Partnership

To address this situation the University of Pennsylvania, the Decatur Community Association, located centrally in the LHWA reticulation area, and a local physician formed a partnership that successfully obtained an environmental justice research grant from the National Institute of Environmental health Sciences (NIEHS). The proposal incorporated a Community Advisory Committee (CAC) to advise on all aspects of the study from a community perspective. The research was designed to determine (1) whether blood PFOA levels were elevated in the community, compared with Philadelphia residents and with published population values, (2) if blood PFOA levels were elevated whether the source was air, water, other or some combination of exposures and (3) if levels were elevated were there changes in certain biomarkers of potential toxic effects. The study collected data from a stratified random sample of residents in the LHWA reticulation area.[19,20]

Development of the Community-First Communication Strategy

The CAC included representation from local townships within the LHWA district, Ohio State and Federal EPA, local school district, and the County Health Department, with the university researcher, local physician and Community Association Trustee as ex-officio members. The CAC, met quarterly in meetings open to the public, worked very effectively, and served as the primary vehicle for community involvement.

After data had been collected from participants, but before any results were available, the CAC discussed and developed a communication strategy. The CAC developed a set of principles (presented in Table II) to guide the investigators as to the community's desires around communication of individual and group results, and the recommended priority sequence for receipt of these results. Through these instructions the community was able to exert ownership over the process of communicating the research results, even though many others might participate in communications and ultimately the press would report the published results independent of the community or investigators.

The CAC recognized that communication of the results would have two components, individual, personal test results to be provided to each participant, and group results addressing the scientific questions to be provided to participants, the community at large, and other stakeholders. Because there was little information available in the scientific literature to define the health effects associated with various blood PFOA levels, an individual would likely need access to the group results to help understand the significance of their own results. Accordingly the communication strategy was designed to incorporate dissemination of both personal and group results. The recommended order for receipt of study results was: 1) study participants, 2) the community i.e. residents of the LHWA district, 3) CAC members, 4) relevant authorities and representatives (County and State Health Departments, State Department of Environment, local water authorities, state and federal elected representatives for the area, local townships, sheriffs departments), 5) local medical providers, 6) local media, 7) national media, as necessary, 8) scientific community, national and international government agencies, industry, legal profession.

Process of Dissemination of Results

The results of the study are described in detail elsewhere.[19,20] Briefly we found that blood PFOA levels were very high, at least compared with other studied communities or any studied general populations in the US. The mean blood PFOA level for those whose primary residential drinking water source was LHWA was 340 ppb, compared with the US mean of ~5ppb. The distribution of serum PFOA was age-dependent, with significantly higher values in children aged 5 or under, and in those over 60. The predominant source of PFOA was residential drinking water, except in workers employed in fluoropolymer production, in which the source appeared to be a combination of residential drinking water and occupational exposure. PFOA levels in the blood of individuals drinking the PFOA contaminated water were approximately 100 times higher than the levels in the corresponding residential drinking water. Our study also examined whether there were signs of toxic effects of PFOA in the residents. Fortunately for this community we did not find any associations between PFOA levels and changes in liver function (the most sensitive effect in animals) or other biochemical markers of possible PFOA toxicity. However our study was not designed to address whether PFOA was associated with cancer or any effects on childhood development which, based on the information from toxicity testing, were of concern to the community..

The community-first communication strategy used to communicate the study results to the community incorporated a specific sequence of timed releases. Blood PFOA results,

accompanied with interpretive displays of the group results, were first sent to individual participants. Local physicians associated with the study were available to answer questions from these individuals about their results. The next day, a summary of aggregate results were sent to relevant authorities and a press release was issued. The press release announced that PFOA levels were high, that water was the main source, and that community members were invited and encouraged to attend a community meeting in the local high school auditorium where detailed results would be presented. At that meeting full study findings and recommendations were presented followed by a questions and answers. A summary of results and recommendations was included in the regular study newsletter to all LHWA district residents. Results, recommendations and answers to frequently asked questions were posted on the study website. Subsequent to the local presentation, summary results were sent to non-local authorities, presentations were made to scientific meetings, and publications occurred in the scientific literature.

Success in Overcoming Disparities

Outcomes of Community-First Communication

Success of the novel communication method was demonstrated by various outcome measures and behavioral changes. Our recommendations, developed in part on grounds of prudence, included use of bottled water wherever water polluted with PFOA might be ingested, reduction of emissions from the plant, institution of water treatment, revision of "safe levels" for PFOA in water, and use of water filters(not generally recommended). Additional recommendations addressed PFOA contaminated well-water. On the day of the public meeting the facility responsible for the pollution announced that free bottled water would be provided to the community, an offer accepted by 78% of eligible households. A follow-up study of study participants showed 95% percent of study participants had made some change in their water source, most to bottle water, but also some other changes; most changes were closely related to the timing of study communications. We observed that provision of information first to the community, but also to other stakeholders, had resulted ia a variety of solutions to the issue of polluted residential water, a process we have termed the development of a "free-market of community-level solutions," see Emmett et al.[21] for details. Follow-up study participants had a median reduction of 26% in blood PFOA. Study results have subsequently been used by several states including New Jersey and Minnesota, to set new drinking water quality standards[22] and by the USEPA and DuPont Company[23] to develop a consent agreement to provide bottled water to other communities where PFOA in water exceeds 0.5 ppb. The community first communication did not impede subsequent publication in peer-reviewed journals. The method of community-first communication was positively received. A local journalist who has independently wrote a book on the pollution episode[24] devoted a chapter to the study and its results and particularly described the first announcement of results locally, "which mightily inconvenienced the droves of industry, legal, government and media people who had to travel to be there for the major announcement". The CAC found that the process informing the participants and community first had been respectful of the community.

Trust

Trust and credibility enabled the community-based collaborative partnership to eventually overcome informational disparities and disempowerment. Trust was built through community involvement at the input, process, and outcome levels.[25] The community was involved at all stages through open processes and communication, including by defining a communication process that was empowering and met community needs. Two other elements contributing to trust were scientific credibility and independence. The study remained credible through the quality of the science. Neither the study design, with a

stratified random sampling of residents, nor the results became contentious, thus the results were accepted by all stakeholders, without themselves becoming the center of controversy. Peer-reviewed publications and subsequent awards such as first place at the 2006 EPA Science Fair continued to enhance the "community study" credibility. Independence from all other interested parties was very important to the community. Despite many interested stakeholders, with funding entirely from the NIEHS, the research partners were beholden to nobody else, allowing the scientific results to speak for themselves. The importance of independence was demonstrated when the community association strongly resisted a request to cooperate with a study group assembled by plaintiff attorneys and the corporation under a court agreement, feeling that the strict independence from all other interested parties might be undermined.

Conclusion

Scammell et al.[26] found that tangible evidence, trust, and power influence a community's perceptions of findings from environmental health studies conducted to address community environmental health concerns. Information possession and flow reflect power, and information disparities are an integral part of the plight of disadvantaged communities. It is accepted in the field of communication that "the medium is the message." An essential part of that medium is the processes of communication and the sequence in which that information is released. Despite developments such as CBPR the usual information flow for research can reinforce the power imbalance between the community and other involved parties. This example shows that credible community-based research together with a community-first communication model, can not only reverse long-standing and deep-seated power imbalances between the community, government agencies and industry, but also lead to a remarkably high level of uptake of public health recommendations. Both can make an important contribution to reversing environmental injustice.

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TABLE I

Information Disparities Between the "Potentially Affected" Community and Government and Industry Stakeholders (See text for details)

Compared with Industry
• Lack of Technical Expertise
• Lack of representation on Advisory Committees to State of Virginia Department of Environmental Protection establishing "interim" action level.
• Lack of access to information/ability to conduct Toxicological Testing
• Lack of ability to conduct/ability to conduct epidemiologic studies of exposed workforce.
• Limited capacity to develop detailed submissions to regulatory processes.
• Lack of detailed day-to-day information about presence/levels of chemical in environmental media including water. Acccentuated by refusal of commercial laboratory to test samples submitted by Water Association.
• Substantial (many years) delay in disclosure that chemical was present in drinking water.
• Lack of authority or ability to influence level of discharges or control measures at the industrial facility.
Scientific publication paradigm and processes that virtually ensures industry access to research results before community.
Compared with Governmental Regulators
• Lack of Technical Expertise
• Lack of representation on Advisory Committees to State of Virginia Department of Environmental Protection establishing "interim" action level.
• State of West Virginia regulates activities and discharges for industrial facility responsible for pollution: exposed residents live in Ohio
• Scientific publication paradigm and processes that virtually ensures govenmental access to research results before community
Lack of authority to monitor or influence discharges from industrial facility

TABLE II

Principles for Communication of Results Developed by the Community

The pre-determined set of principles established by the CAC to govern the process of disseminating study results. Adapted from Emmett et al. [21]

- Results should be released promptly, but not before the investigators were comfortable to do so.
- Individuals participating in the study should receive the results first; to avoid participants first learning results from the press, neighbors or friends.
- The press should be informed in a timely way, and in a manner that allowed the investigators to control the message as far as possible.
- Questions from individuals should be answered promptly
- The study must remain a credible source of information
- Communications should maximize constructive responses to the findings
- Communications should minimize pointless concern.