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Reflexive Research Ethics for Environmental Health and Justice: Academics and Movement-Building

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Abstract

Community-engaged research on environmental problems has reshaped researcher-participant relationships, academic-community interaction, and the role of community partners in human subjects protection and ethical oversight. We draw on our own and others' research collaborations with environmental health and justice social movement organizations to discuss the ethical concerns that emerge in community-engaged research. In this paper we introduce the concept of *reflexive research ethics*: ethical guidelines and decision-making principles that depend on continual reflexivity concerning the relationships between researchers and participants. Seeing ethics in this way can help scientists conduct research that simultaneously achieves a high level of professional conduct and protects the rights, well-being, and autonomy of both researchers and the multiple publics affected by research. We highlight our research with community-based organizations in Massachusetts, California, and Alaska, and discuss the potential impacts of the community or social movement on the research process and the potential impacts of research on community or social movement goals. We conclude by discussing ways in which the ethical concerns that surface in community-engaged research have led to advances in ethical research practices. This type of work raises ethical questions whose answers are broadly relevant for social movement, environmental, and public health scholars.

Keywords

research ethics; community-engaged research; reflexivity; community-based participatory research; environmental health; environmental justice

Introduction

For decades, academics in the United States have simultaneously studied and supported the anti-toxic and environmental justice social movements. Community-engaged research on environmental problems that also supports these movements' policy objectives has reshaped the research enterprise in terms of researcher-participant relationships, academic-community interaction, and the role of community partners in human subjects protection and ethical oversight.

In this article, we draw on our experiences conducting community-engaged sociological and public health research with environmental justice and anti-toxics social movements to develop an expanded conception of research ethics as *reflexive research ethics*. Using this

concept, we move ethics beyond formal guidelines and pre-established professional codes of conduct to consider the relational nature of social movement research and complex questions of reciprocity, control over and access to research data, and research integrity. We describe the environmental justice and antitoxics movements, highlighting connections between academic researchers and their community partners, and provide an overview of community-based participatory research (CBPR) as one form of community-engaged research. We argue that doing CBPR presents new moments of ethical uncertainty which cannot always be resolved through adherence to existing research practice, and thus require a commitment to reflexive research ethics. We discuss ethical concerns in community-engaged research related to the bi-directional impacts of academic research and social movement activity, drawing on our research with community-based organizations in Massachusetts, California, and Alaska. We conclude with a discussion of how this reflexive and relational approach to research ethics can impact and improve the institutionalization of research ethics. Community-engaged research has contributed to advances in research ethics which are broadly relevant for social movement scholars, social scientists, and environmental scientists.

Social Movement Research and Research Ethics

Research ethics are often understood as ‘a rather static set of standards for conduct based on a system of moral values’ (Smith-Doerr 2006), operationalized through professional codes of conduct and formalized through the Institutional Review Board (IRB) protocols that outline acceptable research practices. IRBs are centered around the Belmont principles of ethics, including respect for persons, autonomy, beneficence, and justice, which are central to community-engaged research. Belmont ethics provide valuable guidelines and minimum standards of respect for and responsibility to human subjects for all researchers. But while formalized ethical protocols provide clear and structured sets of guidelines for research, they are unable to fully take into account the dynamic relationships between multiple parties or the constant uncertainty faced by researchers as they navigate new ethical terrain or face questions unaddressed by existing standards.

While ethical uncertainty undoubtedly exists in all types of social science research, we have found that uncertainty is especially pervasive and salient during research that engages directly with communities and social movements. Ethical uncertainty is particularly acute in situations such as those that involve emerging technologies or research practices; power relationships between researchers and communities; norms that vary across communities; research benefits that are distributed across multiple communities; and conflicting individual, professional, and community goals. We have found that these uncertainties are not fully addressed by formal ethical guidelines, and are not necessarily resolved by adhering to them. Indeed, ethical considerations are highly connected to uncertainty, since if there was certainty about the nature of situations, we would likely not have ethical issues (Swauger 2011).

This raises the question: without a formal ethical roadmap to follow in these moments of uncertainty, how should researchers engaged with communities and social movements proceed in an ethical manner? We take inspiration from the widespread call in sociology for reflexive and relational research (Emirbayer 1997, Giddens 1984, Bourdieu 1992), and use this approach to re-conceive of ethical research conduct. Reflexivity has taken on different and sometimes contradictory meanings. For example, reflexivity is understood as a process of modernization that includes self-conscious monitoring (Giddens 1991) and individualization (Beck 1992); a necessary methodological intervention about one’s role as a researcher (Pillow 2003, Kenway & McLeod 2004); a practice of considering power in the construction of knowledge (Callero 2003); and an interrogation of academia’s intellectual

bias (Bourdieu 2000; Schirato and Webb 2003). But while reflexivity has become a major theoretical and methodological influence in the social sciences, the relationship between reflexivity and ethical research conduct has yet to be sufficiently elaborated.

We introduce the concept of *reflexive research ethics* as the self-conscious, interactive, and iterative reflection upon researchers' relationships with research participants, relevant communities, and principles of professional and scientific conduct. We conceive of ethical conduct in research as that which maximizes beneficence and minimizes harm. Beyond this general understanding of ethics, reflexive research ethics does not assert a set of preconceived principles of how a particular moment of ethical uncertainty should be addressed; rather, it entails the continued adjustment of research practice according to more relational and reflexive understandings of what might be beneficent or harmful. Our conception of reflexivity thus fits with concerns about the partiality of perspectives in the research process; the effects of researchers on society; and the nature of structural and spatial power relations between the researchers and researched. Further, we view reflexivity as not solely an individual endeavor, but rather as a collective relationship between all actors in the research process.

Conducting research with environmental health and justice organizations has shown us how ethical research is relational, in that it involves connections and exchanges between multiple parties. This type of research demands researchers' awareness of their relationships with research participants, institutions, professional disciplines, and the larger community and consumers of the knowledge generated. Thus, through reflexive research ethics, we propose that when conducting research involving the daily lives and concerns of people, communities, and social movement organizations, researchers must move beyond understanding scientific ethics as static, pre-conceived standards or guidelines to seeing research as a process that is embedded in social relationships and has social consequences.

Practicing reflexive research ethics requires researchers to identify and establish interactive discussions with the full range of publics relevant to their work, including research participants, local communities, academic disciplines, and people potentially impacted by research findings. Researchers must also identify norms and principles that govern their research; draw upon accumulated knowledge of how others have conceptualized, addressed, and reflected upon relevant ethical issues; assess ethical tensions which may arise from the prioritization of particular interests, publics or principles; and respond to emergent ethical tensions.

This concept builds on a "post-Belmont" conception of ethics, which asserts the need for a holistic approach to conducting ethical research that balances the application of Belmont principles at both the individual and community levels (Brown et al. 2010). In this approach, community harm and benefit is strenuously taken into account, as well as individual harm and benefit. Sharing information is emphasized, in contrast to IRBs' frequent mode of withholding information for fear of alarming people.

The ethics of conducting social movement research are often discussed in terms of questions that arise during fieldwork or ethnographic practice, such as researchers' identities in relation to the social movement they are studying, questions of access to data, and dissemination of research findings (Atkinson 2009, Hammersley and Atkinson 2007, Murphy and Dingwall 2001). Our concept goes farther to suggest that reflexive research ethics should govern all phases of the research process, including the *identification* of research questions and motivation; the *engagement* with community actors, social movements, knowledge institutions and other publics; the *production* of knowledge; the *interpretation or analysis* of data; the *presentation and dissemination* of research results; and

the *use* of scientific knowledge. This aligns with Blee and Currier's (2011: 404) point, introducing a special issue of *Qualitative Sociology* on "Ethics Beyond the IRB," that "ethics are involved at every stage of research." Reflective research ethics thus are connected to the scientific uncertainty that arises throughout the entire research process, raising context-specific, relational and value-laden ethical dilemmas for researchers across a range of disciplines and methodological orientations.

Social Movements Meet Academia

Academic disciplines that address the connection between human populations and the natural environment, such as environmental sociology and environmental health science, have long grappled with co-participation, in which scholars have been involved in movements that they are also studying. As a result, these fields have, to varying degrees, been shaped historically by their interaction with social movements and community actors, and in turn, influenced the trajectories of social movements.

Although environmental and public health concerns were long part of labor and urban social movements starting in the late 19th century (Gottlieb 1993), environmental sociology grew up as a research discipline contemporaneously with the modern mainstream environmental, anti-toxics, and environmental justice movements, focusing on topics like ecological limits, economic growth and increased affluence, and environmental activism (Dunlap and Catton 1979, Dunlap and Mertig 1992, Cable and Cable 1995). Similarly, the environmental justice focus within environmental sociology that emerged in the 1980s directly integrated with social movements working against issues of community contamination, particularly in the US South (Bullard 1990; Mohai et al. 2009). The environmental justice movement was galvanized by a strong connection to civil rights struggles and by empirical data generated by social scientists that revealed that polluting hazardous waste facilities were disproportionately located in African American communities (Mohai and Bryant 1992). More recently, as environmental justice social movements have extended to areas such as food justice and climate justice, environmental sociology has followed in its path.

Although environmental epidemiology, exposure science, and environmental toxicology have not been as activist-oriented as environmental sociology, some environmental health scientists have engaged with social movements and community-based struggles. In part this was due to the development and growing legitimacy of community-based participatory research (discussed below). There was also another stream where by public health researchers engaged with health activism through community-based organizations and patients' groups, on issues such as AIDS, women's health reforms and reproductive rights (Epstein 2008). This historical co-production of knowledge, principles, identities and priorities between these academic disciplines and relevant social movements, and the recognition that academic research is closely connected to societal concerns, has led researchers in these disciplines to focus on addressing ethical considerations related to research practices.

Community-Engaged Research

From its origins in typically un-funded 'participatory action research' and 1960s federal programs' requirements for public involvement, community-based participatory research (CBPR) grew largely through federal funding in the 1990s. CBPR is conducted as a close, collaborative partnership between academic researchers and community organizations as partners and co-researchers. In a CBPR project, research is oriented to the needs of communities and all partners are involved at every stage of the research process. CBPR projects generate scientific knowledge, improve public trust and understanding of environmental health science, inform culturally and socially appropriate intervention

methods, and improve public health decisions (O'Fallon and Dearry 2002, Minkler and Wallerstein 2008).

CBPR has been closely connected with environmental justice, both in funding mechanisms and in preferred research arrangements by environmental justice groups. Social scientists have played a central role in the expansion and institutionalization of federally-funded research on environmental justice, especially through programs funded by the National Institute of Environmental Health Sciences (Baron et al. 2009, O'Fallon and Dearry 2002, Senier et al. 2008). Not surprisingly, professional recognition, publication opportunities, and university training programs have grown in tandem with such funding (Brown et al. 2010).

Rather than follow only the interests and scientific objectives of researchers, CBPR is inherently relational in that the research must address issues affecting community partners, be geared toward building community capacity, and report findings using accessible language and in a manner that is respectful of community needs. CBPR researchers have often sought to correct the perceived ethical shortcomings of studying communities and social movements without providing direct benefits. In all phases of research, CBPR projects are guided by ethics of mutual respect, open communication, and recognition of knowledge, expertise, and resource capacities of all partners, seeing them as co-learners and co-owners of data (Israel et al. 1998).

There are other forms of community-engaged research in environmental health sciences and environmental sociology. Research can be community-engaged without taking the form of a formal CBPR partnership, as in popular epidemiology (Brown and Mikkelsen 1990), citizen-science alliances (Morello-Frosch et al. 2006), and the community outreach and engagement cores of federally funded research centers (Brown et al. 2010). Such approaches demonstrate that community-engaged research can be conducted in accordance with service and outreach goals, without the formal partnerships between researchers and community organizations that characterize CBPR. Practitioners of these approaches are similar to CBPR adherents in that they generally view their approaches as driven by ethics of individual empowerment, community empowerment, and scientific and governmental responsibility to serve the public good.

The practice of CBPR constantly presents new moments of ethical uncertainty that cannot necessarily be resolved through adherence to existing practice or fixed ethical guidelines alone, including power relationships between community groups and the academic researchers who often have the funding and initiate research projects; racial, ethnic, gender, and cultural dynamics; questions of data ownership; conflicts between individualistic and community-minded conceptions of ethical responsibility; distribution of benefits from research; and the programmatic requirements of funding agencies or foundations (Bastida et al. 2010, Brugge and Kole 2003, Minkler 2004, Giese-Davis 2008). Scholars have also discussed the challenge of conducting community-engaged research in which ethical concerns go above and beyond those clearly governed by IRBs (Brown et al. 2010, Flicker et al. 2007). These multivalent power dynamics make reflexive research ethics particularly salient for community-engaged research. Thus, practicing CBPR demands the reflexive approach that is central to our concept of reflexive research ethics.

Our Research

This paper identifies ethical concerns common in community-engaged research that are broadly relevant to scholars studying social movements. We discuss two general areas of ethical tensions and uncertainties that we have encountered in community-based research: the impact of research on social movement goals, and the impact of social movement or community goals on the research enterprise. We give examples of research practices that

build and maintain relationships between academic and community partners, and that treat research as a series of responsibilities to communities, publics, and research integrity.

The examples below are drawn from our own work and that of our colleagues. In particular, we refer to three research partnerships that have been central to our research efforts in the last ten years, all of them in the United States. In this paper, we will not provide full background information on any of these projects, as more information on the research is available from the associated citations for each project. In Massachusetts, we have collaborated on household exposure and biomonitoring studies¹ with Silent Spring Institute, a non-profit research organization that studies the links between women's health and the environment (Altman et al. 2008, Brown et al. 2010). In California, we have conducted a household exposure study and a health survey with Communities for a Better Environment, a community-based environmental justice organization working in an urban industrial neighborhood (Brody et al. 2009, Brown et al. 2011, Cohen et al. 2011). In Alaska, we have worked with Alaska Community Action on Toxics, the state's only environmental health and justice nonprofit, on environmental justice concerns related to military bases and former industrial sites, persistent chemicals, and reproductive toxics (Altman 2006; Altman 2008). We use examples from these cases to highlight common ethical concerns, describe our attempts at reflexive research ethics, and suggest the implications these ethical concerns have for other social movement researchers.

Impacts of the Research Process on Social Movement Goals

Researchers of social movements have responsibilities to the communities and individuals they study. Researchers have to balance harms with benefits, which includes informing people of possible harms they may experience in the course of the research and responding to the needs of research participants and collaborators. The research process can contribute to social movement goals, but at other times it has the potential to hinder them.

There are myriad potential negative impacts of unethical engagement of researchers with social movements and communities. One such practice has been termed 'parachute research' – dropping in to collect data without engaging with the community, and then leaving without sharing the data and results (Costello and Zumla 2000). In such cases the impacted community has not been engaged in the various steps in the research process, such as the development of research questions, the analysis of findings, the compilation of data, or the development of policy prescriptions. This practice also diverts a community's time, labor, energy and resources into data gathering or participation in a study, without providing perceived or accessible benefits. In addition, more severe impacts can include inciting conflict between community organizations, the use of study results to support the adoption of policy measures that are deemed unfavorable by community members, data use that has unintended consequences (such as decreasing a neighborhood's property values due to publicity of contamination), and a strained financial and administrative relationship between the research institution and the community.

Reflexive research ethics can help researchers who work in communities navigate the difficulties of conducting community-engaged research within the codified ethical guidelines required by IRBs and other formal or informal academic practices and expectations. When addressing ethical challenges it is important to incorporate contextual and relational knowledge in addition to more general understandings of responsible research practice. For example, we often work with community partners in the study design phase to

¹Exposure research and biomonitoring measures the presence and accumulation of chemicals in household environments, such as dust, or human tissues, such as blood.

clearly outline our scientific and policy objectives for a collaborative project, and then work to design a study protocol and results dissemination plan that will address mutual organizational interests. Our reflexive, iterative approach to the co-production of scientific knowledge allows our research to advance the social and environmental health science fields while simultaneously supporting our community partners' environmental health and justice goals of education, public awareness, and regulatory change. Here we discuss three ethical tensions and how we dealt with them through a reflexive approach to the ethical practice of research.

A first tension we have repeatedly encountered is that certain requirements of academic research can conflict with the goals and needs of community organizations. Sometimes social movement organizations approach researchers to collaborate on specific research projects that are relevant to scientific, regulatory or advocacy goals, which may or may not coincide with academic pressures to rapidly publish results, or with financial or disciplinary constraints on study design. However, a reflexive approach to research can often unite the goals of research partners. For example, Silent Spring Institute asked us to examine the history of lay involvement in federally funded research and services, in order to justify lay involvement in breast cancer research. The organization also sought our help in communicating with the Massachusetts Department of Public Health about the scientific, logistical and practical rationale of preserving exposure sampling data for future analyses that could have public health benefits. Another organization, Communities for a Better Environment asked us to provide briefing papers for city officials in order to facilitate organizing against a planned oil refinery expansion adjacent to the community. A third organization, Alaska Community Action on Toxics, asked us to write and later revise a brochure on reproductive health for physicians. Some of these requests (e.g. physician brochure) were straightforward in that they did not lead to potential conflicts with our university officials. But others, including a request by community partners to store sampling data after a study finished, had more potential for conflict. In this instance, we pursued multiple rounds of protocol revision with our IRB, which expressed concerns about informed-consent procedures should researchers conduct additional and unexpected analyses in the future. In doing so, we strengthened our relationship with IRB officials and developed an improved informed-consent document useful for future research projects.

This example connects to a second tension: researchers and communities face multiple difficulties when trying to combine the reflexivity of community-engaged research with the codified ethical guidelines required by IRB protocols. Community-academic collaborations involve numerous ethical decisions that move far beyond the formal ethics encoded into an IRB protocol or professional standard of ethics. This post-Belmont approach to ethics, described above, requires that both researchers and community partners play a central role in developing study protocols that ensure the protection of study participants. For example, a colleague involved in a research partnership with a community asked us for guidance after their IRB denied a research protocol which would have tested for chemicals in breast milk. The IRB argued that women would reduce breastfeeding if they found that their breast milk contained contaminants, but we drew on existing research on women's perceptions of biomonitoring (Wu et al. 2009) to show this not to be the case.

In another example, in our household exposure and biomonitoring work we have collaboratively designed study protocols so that individual participants have access to their personal exposure results if they choose, and individual- and aggregate-level report-back protocols are fully deliberated before results dissemination. However, this form of individualized results communication is controversial: some IRBs question whether uncertainty regarding the health effects of contaminants or the lack of clear strategies to reduce exposures can cause undue worry and stress among study participants. Our research

documents that study participants generally want access to their personal data, even when the implications of contaminant exposures for future health effects are not well understood (Altman et al. 2008). Through our community collaborations, we have developed innovative methods for reporting back individual biomonitoring results, and have conducted follow-up interviews with participants to learn how they respond to receiving their results and how they use the information (Adams et al. 2011, Brody et al. 2007).

A third tension relates to communicating results to communities. Although communities should not receive individual-level results except in particular circumstances and only with the expressed consent of participants, community-level results such as average exposure levels or suspected links between pollution sources and exposure often should be communicated. Environmental health researchers have documented how individual- and community-level results can be communicated in ways that work to overcome information disparities between researchers and participants (Emmett and Desai 2010, Morello-Frosch et al. 2009). In other instances when working with Native tribes, tribal IRBs have specific requirements governing community-level data communication and ownership (Watkins et al. 2009).

In our work, community report-back is coordinated through partnerships with community organizations. For example, we disseminated community-level results from an exposure study and a health survey at public forums organized by our community partner, Communities for a Better Environment. Because these forums were organized by an established community organization, they were well attended and attracted the attention of local civic leaders, meaning that our research likely reached a wider audience than it would otherwise. By closely collaborating with social movement organizations, researchers can release results to the community before publishing them in scientific journals or discussing them with the media. For example, colleagues have described community meetings that were closed to the media days or hours before scientific publications or press conferences, to ensure that the first to hear about results are those most directly affected by them. This example of timely dissemination of findings demonstrates one way of respecting the community's interest in co-directing the dissemination of study results, while ensuring timely and productive publication for academic partners.

Overall, our understanding of ethics in research has been largely shaped through active investigation into the ways in which our research has beneficial or detrimental impacts on social movement and community partners. At several points throughout a multi-year research project, we engage in mutual assessment and evaluation (through debriefings, anonymous evaluations, and short interviews) in formal and informal meetings, to learn and assess how partners experience the academic-community collaborations as they evolve and whether they meet diverse objectives, needs and goals. These ongoing reflexive exercises help to ensure that emerging ethical problems are uncovered and addressed in a timely way.

Although CBPR principles can suggest ways to advance this reflexive process, they do not automatically guarantee public representation or involvement in the development of study protocols and application of ethical principles. Researchers should recognize that community groups may not be synonymous with or fully representative of the communities in which they work or the constituencies that they purport to serve. Thus, ethical research also involves being attentive to the heterogeneity of interests, needs, and demographics within a particular movement, group or community. And further, it requires researchers to be aware of which publics their research seeks to serve.

Impacts of Social Movement and Community Goals on the Research Process

Research that is attuned to social movement goals and community needs has great potential for producing relevant and useful science. But there are also potential pitfalls if the researcher is not also committed to the integrity of scientific practice, and cognizant of the reality of research constraints. This situation raises ethical challenges related to balancing community or organizational concerns with scientific standards and professional obligations.

Lay identification of research questions has long benefited science, as with worker and union identification of major workplace hazards such as asbestos, cotton dust, vinyl chloride, and lead (Mayer 2008). Much of what we know about major contaminants comes from residents who report on their exposure-related symptoms (e.g., Brown and Mikkelsen 1990). The dramatic increase in research on asthma was largely initiated by inner-city parents and teachers who noticed its growing prevalence (Corburn 2005). If the goal of science is to gain new knowledge to make a better society, lay-initiated science has certainly shown its value in identifying emerging issues and preventing disease.

But this research must also be ethical in conforming to professional scientific standards of producing reliable and truth-oriented knowledge, whether in social science, epidemiology, or toxicology. To offer a hypothetical example, a researcher works with a community group but finds that the study results contradict community beliefs about a particular environmental health problem. The ethical challenge would be how to interpret and disseminate these results. Reflexive, community-engaged research would encourage partners to talk through these scenarios before embarking on a study to decide how they might deal with such a challenge. It also helps to highlight early on the potentially high stakes of future study results and encourages a candid discussion about whether the potential benefits of conducting such a study outweigh the possible detrimental effects on community advocacy efforts.

Researchers also have the responsibility to balance community concerns with scientific constraints. Community groups may seek answers to questions that may be difficult to analyze or assess scientifically. For example, residents in a small neighborhood may believe they have an excess of a disease, and therefore seek an epidemiological health study. Most researchers would point to the difficulty of such a study, in terms of scientific capacity, sample size, and time, and might suggest a more appropriate way to call attention to excess disease, perhaps by documenting high levels of exposure or a putative source of toxic chemicals. Embarking on a research path that researchers knew was flawed would violate professional scientific standards and would ultimately undermine the interests of community partners. Community groups usually understand this, though there are exceptions. For example, a researcher well known for supporting community groups investigated a cancer cluster in proximity to an army base and faced community anger at public hearings after presenting results that did not match with the expectations of local organizations.

In order to address these challenges, we have taken many precautions in developing rigorous research projects that still support organizing and advocacy goals. We engage in community-academic collaboration in the design and implementation of the original study questions and research protocols, as well as in the interpretation and dissemination of data. Ethically-minded community-engaged research can potentially enhance scientific practice through improved research design, smoother project implementation, and more accurate interpretation of findings. By using a reflexive research ethics approach, we engage in the earliest possible discussion of all these issues and create spaces, as discussed above, for active reflexivity throughout the research process. This reflexivity can be somewhat

institutionalized using Community Advisory Boards to hold researchers accountable by providing feedback on both scientific practice and community collaborations. Other communities have done similar things, such as the claimants in the Fernald, Ohio suit that provides medical monitoring for residents near a nuclear weapons facility (Gerhardstein and Brown 2005).

In spite of these potential difficulties, reflexive research ethics can improve the rigor, relevance, and reach of science practice (Morello-Frosch et al. 2005, Morello-Frosch et al. 2011). For example, improved rigor can be seen in a partnership between Alaska Community Action on Toxics and environmental health researchers on indigenous food sources on St. Lawrence Island. Long-term collaboration with residents taught researchers that samples would be most meaningful if collected from hunting grounds which were located near a decommissioned military base (Altman 2008). Improved relevance can be seen in how Silent Spring Institute scientists incorporated the desires of Communities for a Better Environment for volunteers to be added to the household exposure study sampling frame, and they fulfilled the community's desire to look for refinery-related chemicals in environmental sampling, as well as the endocrine disrupters of primary interest to the scientists and their breast-cancer-activist partners (Brody et al. 2009). Improved reach is manifested in how Silent Spring Institute scientists developed visually-appealing, accessible outreach materials that study participants and Communities for a Better Environment organizers could use on their own to disseminate results.

Discussion and Conclusion

The numerous ethical concerns that emerge when conducting research with social movements or communities are best understood as *reflexive research ethics*, a series of responsibilities that researchers have to the multiple publics which their research may impact. Thus, the reflexive researcher will not view ethical practices as static or detached from the universe in which they are developed, but rather as responsive, relational, and often contextual. We developed this concept through our community-engaged work with environmental health and justice organizations, specifically inspired by moments of co-production of knowledge when academics and community partners conduct scientific research collaboratively. This entanglement of the scientific enterprise with social movement and community organizing brings to the surface and amplifies ethical tensions. Thus our concept is particularly relevant for all social movement researchers engaged in co-production of knowledge – not necessarily environmental knowledge – with communities and organizations.

However, we would argue that this constant reflexivity raises questions that all scholars studying social movements should be attentive to, including: How can research be conducted to maximize beneficence and minimize harm at all phases of the project? To whom should researchers be accountable to in terms of their research practice and modes of conduct? And what values and principles should be prioritized in their methods of engagement? The concept of reflexive research ethics does not purport to answer these questions; rather, these are questions that can be hidden in the background of the research process, unless active reflexivity brings them to the surface.

Research integrity is often understood as a commitment to adhering to established principles of research conduct in an unbiased fashion. We challenge this notion that research must be disinterested in order to be done with integrity. Rather, we view research integrity as engaging with ethics as fluid, dynamic and value-laden guideposts that must be constantly and self-consciously reflected upon. Research with community partners has demonstrated to us that the identification of what rights individuals and communities are entitled to and

which practices should be employed are contested issues, and thus demand constant reflexivity on the part of researchers.

However, we have also emphasized that this re-conception of research ethics should not be reduced to simply responding to the interests or expressed needs of individuals, communities, social movements, or other actors. Rather, reflexive research ethics also require a strong commitment to conforming to appropriate professional scientific standards of producing reliable and truth-oriented knowledge. Science must be seen as credible in order to contribute to the legitimacy and successes of community partners. This requires social movement scholars to actively use, but move beyond, the forms of ethical conduct, such as individual informed consent, which can be codified in IRB protocols. IRB requirements are important for research and provide necessary safeguards for research participants, but when studying organizations, communities and groups, IRB ethics often do not go far enough. Instead, seeing ethical obligations as reflexive and relational acknowledges the inviolable importance of informed consent while also recognizing that salient ethical concerns emerge during the course of social movement research that are unavoidably contextual, relational and value-laden.

Not all social movement scholars need to conduct CBPR or community-engaged work, as many research questions are more appropriately answered using other research methods or types of participant observation. However, any research on social movement or community issues can be significantly improved through attention to reflexive research ethics. We are not suggesting that community-engagement is a panacea for ethical concerns. To the contrary, our research documents that community-based research often magnifies or brings to the forefront ethical issues that, in less publically-engaged styles of research, may not demand such high levels of attention or make some ethical conundrums inherent to the research process. Additionally, as CBPR has become more widely accepted, it becomes a potential tool for career advancement, providing further justification for reflexivity in research as researchers should ensure that chosen research strategies and practices remain beneficial for communities. Additionally, community-engaged research on its own is rarely sufficient for addressing problems of serious concern, such as environmental contamination or toxic exposure, that are often central to the missions of our community partners. However, when research actively incorporates community voices and concerns, it may provide solutions to community problems which achieve scientific and non-scientific goals (such as policy-making), and support movements for justice and democratic participation in decision-making processes.

Although the research described in this paper was based in the United States, the reflexivity we advocate might travel well to other countries, especially places where interactions between researchers and participants are marked by complex and uneven relationships of power. Additionally, the questions raised by reflexive research practices about issues such as data access and dissemination, research goals and utility, and human subjects protection are relevant for many types of research, including social movement studies, environmental sciences, and public health. Reflexive ethics are especially important for social movement scholars studying movements whose activities deal with high levels of uncertainty, because the ethical guidelines are unlikely to be written. For example, many environmental health researchers and organizations today conduct cutting edge science that is so new that there is no consensus on what practices are ethical. Engaging around issues of scientific uncertainty requires scholars to work closely with social movement organizations to balance movement goals, research needs, and the protection of individual- and community-level rights. Future research should be directed to uncovering and responding ethically to the tensions that exist in the study of emergent science and its relationship to the concerns of social movements and communities that may be impacted by such scientific endeavors.

We have described how reflexive engagement with research ethics has become increasingly institutionalized by federal funding programs that support CBPR research. We suggest that the National Science Foundation could sponsor a research program on social movements to incorporate high levels of participation and partnership by community organizations, and to actively address ethical concerns including research design and data ownership. Funded research of this type could explore forms of knowledge co-production between social movement scholars and social movement actors, providing new understandings of power relationships and knowledge production. This program could also sponsor conferences and workshops for these types of movement-engaged scholars, providing sites for discussion and knowledge-sharing among researchers and institutionalizing a network of social movement scholars actively thinking about research ethics. Our model also offers possible contributions that move from social movement scholarship to the field of environmental health sciences, since this reflexive and relational approach is clearly relevant to epidemiologists, public health researchers, and exposure scientists who want to conduct relevant, rigorous work on local health problems.

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Biographies

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Phil Brown is Professor of Sociology and Environmental Studies at Brown University, where he directs the Community Engagement Core of Brown's Superfund Research Program, and the Community Outreach and Translation Core of Brown's Children's Environmental Health Center. He is the author of *No Safe Place: Toxic Waste, Leukemia, and Community Action*, *Toxic Exposures: Contested Illnesses and the Environmental Health Movement*, and, most recently, *Contested Illnesses: Citizens, Science and Health Social Movements*, co-authored with Rachel Morello-Frosch and Steve Zavestoski. He is also co-editor of *Illness and the Environment: A Reader in Contested Medicine* and *Social Movements in Health*. His current research includes social policy and regulation of chemicals, ethics of reporting data to study participants, nanoscientists' views of social and ethical impacts, and health social movements.

Rachel Morello-Frosch is associate professor in the Department of Environmental Science, Policy and Management and the School of Public Health at the University of California, Berkeley. Her research integrates environmental health science with social epidemiologic methods to assess potential synergistic effects of social and environmental factors in environmental health disparities. In collaboration with scientific colleagues, she has developed scientifically valid and transparent tools for assessing the cumulative impacts of chemical and non-chemical stressors to inform regulatory decision-making to advance environmental justice goals. She is assessing the application of these methods for implementation of climate change policies in California. She has also written about the scientific challenges and bioethical considerations associated with exposure assessment and chemical biomonitoring research in economically and racially marginalized communities. Her most recent book, *Contested Illnesses: Citizens, Science and Health Social Movements* (co-authored with Phil Brown and Steve Zavestovski) was published in fall 2011. Her research is supported by the National Institute of Environmental Health Sciences, National Science Foundation, US EPA, Cal-EPA, and private foundations.