Research Altruism as Motivation for Participation in Community-Centered Environmental Health Research

Jennifer S. Carrera[a,*], **Phil Brown**[b], **Julia Green Brody**[c], and **Rachel Morello-Frosch**[d]

[a]Department of Sociology, Michigan State University, 509 E. Circle Drive, Room 316 Berkey Hall, East Lansing, MI 48824, USA, jcarrera@msu.edu

[b]Northeastern University, 360 Huntington Avenue, 318INV, Boston, MA 02115, USA, p.brown@northeastern.edu

[c]Silent Spring Institute, 320 Nevada Street, Newton, MA 02460, USA, brody@silentspring.org

[d]U.C. Berkeley School of Public Health, 50 University Hall #7360, Berkeley, CA 94720-7360, USA

Abstract

Protection of human subjects in research typically focuses on extrinsic rather than intrinsic motivations for participation in research. Recent sociological literature on altruism suggests that multiple kinds of altruism exist and are grounded in a sense of connection to common humanity. We interviewed participants in eight community-centered research studies that sampled for endocrine disrupting compounds and that shared research findings with participants. The results of our analysis of participation in these studies indicate that altruistic motivations were commonly held. We found that these sentiments were tied to feeling a sense of connection to society broadly, a sense of connection to science, or a sense of connection with the community partner organization. We develop a new concept of banal altruism to address mundane practices that work towards promoting social benefits. Further, we offer that research altruism is a specific type of banal altruism that is a multi-faceted and important reason for which individuals choose to participate in community-centered research.

Keywords

United States; community-centered research; altruism; participation in research; intrinsic motivation; environmental health; community partners; trust

1. Introduction

The question of what motivates people to participate in research is core to the ethical production of scientific knowledge. Concerns about coercion often dominate discussions

[*]Author to whom correspondence should be addressed; jcarrera@msu.edu; Tel.: 1-517-353-8124; Fax: 1-517-432-2856; Department of Sociology, Michigan State University, 509 E. Circle Drive, Room 316 Berkey Hall, East Lansing, MI 48824, USA.

about motivation for participation and typically consider either appropriate levels of financial compensation to ensure participants are not unduly influenced (Grant and Sugarman, 2004; Singer and Couper, 2008) or issues of power and control between researchers and prospective participants (Appelbaum et al., 2009; Fisher, 2013; Nelson et al., 2011). Over the course of the twentieth century, increased nuance has been given to what it means to eliminate coercion and ensure informed consent, but what motivates participation in a research study is more ambiguous. While it is important to understand extrinsic motivations for participation, such as compensation and intimidation, intrinsic motivations for participation in research have been given less attention in the sociological literature.

Generally, researchers planning studies attempt to minimize risks, but in order to minimize the potential for coercion and exploitation, benefits tend to be limited so that a person could reasonably choose not to participate in the study. Degree of payment for participation is debated among ethicists with some more concerned about possible coercion while others emphasize fair compensation for time or even expenses lost due to absence from work (Dickert and Grady, 1999; Kimberly et al., 2006; Singer and Couper, 2008). For research studies with no therapeutic benefits and modest or no financial compensation for participation, there is an inherent assumption that participants engage in studies for altruistic reasons (Hunter et al., 2012; Williams et al., 2008).

In this paper, through drawing from previous scholarship on altruism, we argue that a sense of empathy and shared connection with others is a key factor in the decision to participate in research. Among participants in two of our team's studies and in six other biomonitoring and household exposure studies, we find that participants feel connected to society broadly, to the scientific research process, or to the community-partner organization. Through a qualitative analysis of motivations for participation in eight research studies that studied community environmental contaminants and knowledge sharing between researchers and study participants, we find that existing concepts related to altruism insufficiently capture everyday practices that can be characterized as altruistic. To address this gap, we develop the new concept of banal altruism. Secondly, given our specific attention to altruism within the research setting, we propose that research altruism is a specific form of banal altruism that provides motivation for engagement in community-centered research studies. To the extent that such studies take place in the framework of community-based participatory research (CBPR), we understand that this approach explicitly counters coercion and exploitation, thus leaving people greater latitude to be willing participants, and even more so, to strongly desire to participate for the altruistic reasons we describe.

2. Background Literature

Numerous studies have shown that altruism is a factor in why people participate in research (e.g. Beskow et al., 2011; Hanson et al., 2015). In particular, research on participation in HIV vaccine trials showed that altruism, among several factors, encouraged engagement (Brooks et al., 2007; Chin et al., 2016; Newman et al., 2006). Altruism, with few notable exceptions (see Chin et al., 2016), typically is treated as a static and uniform concept with little nuance and that exists distinctly from other measurable motivations (e.g. Newman et al., 2006). Given that trait-like psychological approach, sociology has often viewed altruism

with critical skepticism. Here we seek a better understanding of how this concept operates within a context of complex human emotions, research practices, and social structures.

Sociological treatment of altruism is relatively recent and a section of the American Sociological Association addressing the topic was not formed until 2011. Sociologists define altruism as intentional, voluntary behavior that is meant to improve another's, but not one's own, condition with no expectation of personal reward (Simmons, 1991). In this way, early work on altruism and contemporary critiques of the concept suggest that altruism is never truly possible, since all behavior can be retrospectively understood in terms of self-interest (Piliavin and Charng, 1990). This basic assumption underlies the rational-choice perspective of economic theory which asserts that all choices can be understood within a frame that maximizes benefits and minimizes costs. Within this approach all choices become evidence of some benefit, even though an actor in a real situation does not have the benefit of hindsight in making decisions. Indeed, bringing goodness into the world may be a reward on its own. Contemporary scholars of altruism move beyond this impasse and entertain that, while the ideal type of altruism without any personal gain is theoretically improbable, people do engage in generally selfless behaviors that can be studied.

Bykov's (2016) review of theoretical frames on altruism outlines three dominant approaches: altruism as a biological act of evolutionary self-preservation; altruism as an individual psychological motivation to do good and be viewed as a good person; and, sociologically, altruism is a shared moral norm for behavior. Three types of altruism that exemplify biological motivations for altruism include evolutionary altruism, in which one operates without time to think of consequences during an emergency (Piliavin and Charng, 1990); kin-selected altruism, in which blood ties encourage apparently selfless behavior; and reciprocal altruism, wherein those who are not related exchange favors with each other (Humphrey, 1997).

A common psychological form of altruism is vernacular altruism, where one is motivated by helping others (Humphrey, 1997). Within this understanding of altruism, one important factor that seems to drive altruistic behavior is a sense of empathy towards an impacted population (Oliner, 1991; Piliavin and Charng, 1990). Using a psychological frame, empathy may be viewed as an individual, psychological character trait or, using a sociological frame, it may be viewed as a socialized appreciation and sense of connection to others. The more individuals can appreciate the experiences of an impacted population and imagine themselves in a similar situation, the more likely a person will be to engage in altruism. In this vein, Kristen Monroe (1996) has argued that altruism stems from a sense of connection to broader society through common humanity.

While some have argued that altruism involves a conscious choice to act against one's own self-interest (Wexler, 1981), others have suggested that altruism is a form of disinterested love (Neal, 1982). We explore disinterested love through bureaucratic practice. For this we draw inspiration from Hannah Arendt's (1963) analysis of the banality of evil where she proposed that evil does not need to come from intentionality (i.e. the desire to cause harm), but instead can come from bureaucratic processes that represent a mechanical and disinterested set of behaviors that lead to social harm. Understanding altruism as

disinterested love, we propose that a new form of altruism for consideration is *banal altruism*, wherein bureaucratic practices also have the potential to lead to positive social benefits.

In this paper we ask, what is the role and character of altruism that motivates participation in community-centered research studies? Through this analysis, we elaborate on Monroe's general sense of connection to a common humanity by exploring the specific appeal of participation in community-centered research studies. We consider that a general sense of connection to others can facilitate engagement in sometimes mundane bureaucratic processes, which we characterize as banal altruism. Given that the form of banal altruism that we expand upon in this paper is specific to the context of participation in research studies, we refer to this specific engagement as research altruism.

3. Methods

In order to study intrinsic motivations for participation in research, we evaluated factors related to individual participation in eight community-centered research studies that examined chemical exposure and/or chemical body burden. All of the studies were originally conducted to study biomonitoring and/or household exposure for endocrine disrupting compounds and other contaminants. Each of these studies involved a community partner organization in addition to the scientific research team. Two of the studies were conducted by our research team and the other six were conducted by other research groups.

The studies initiated by our team include the Cape Cod Household Exposure Study (CCHES) and the Northern California Household Exposure Study (NCHES). In the original monitoring study on Cape Cod, led by Silent Spring Institute, 120 participants were selected to be part of a household exposure study that collected urine and dust samples. It was only after hearing participants' questions in community meetings that our team decided to return with interviews dedicated to the "exposure experience," i.e. the manner in which research participants in exposure studies make sense of personal, familial, community, and societal impacts, as well as how they assign blame and responsibility for remediation, prevention, or justice (Altman et al., 2008). Of the women who received their results, 25 were given follow-up interviews between June 2005 and May 2006.

When the Northern California Household Exposure Study was designed, it included at the outset such interviews as central to the research project. Communities for a Better Environment (CBE) in Richmond, California was the community partner for the NCHES (Brown et al., 2012). This study was established as a comparative study to the CCHES and between 2004–2009 our team replicated the sampling procedures for endocrine disruptors in 40 homes in Richmond and 10 homes in Bolinas, California. Thirty-two of 50 total participants were interviewed about their motivation for and their experiences with participation in the study.

Our desire to learn about the motivation to participate in and the impacts of participation in community-centered research studies led us to reach out to six additional research teams engaging in similar work to include their experiences in our analyses. We were able to gain

access to these studies because of our team's success in designing right-to-know-based approaches to sharing research data with participants. These experiences led to numerous requests to speak about this topic and help other researchers develop approaches to reporting results back to participants. In response to these experiences, our team designed a funded project to examine how such democratic report-back processes were conceived of and carried out by other researchers. Several of the studies involve longitudinal cohorts and data collection is ongoing for some of the projects. Recruitment for these projects by their own investigators began as early as 1999 and ended as recently as 2013; our engagement began in 2010. We gained permission from the PIs of each study and from the IRBs that covered them. Interview questions were based on those we used in the two original household exposure studies and were standard across all studies, but we included additional details concerning the contaminants of concern, which varied across studies.

Study 1 involved sampling blood and breastmilk from more than 300 residents of a Midwestern community and testing the samples for perfluorooctanoic acid (PFOA), a probable human carcinogen used in the manufacturing of Teflon. Sixteen participants in the original study completed follow-up interviews with our team. This study was motivated by known high levels of water and air contamination from Teflon production at a nearby chemical plant. The community is predominately white, low-income, and has high unemployment.

Study 2 started following a group of more than 500 children born in a western state from birth through development. Twenty parents of children from the study completed follow-up interviews. Agricultural communities are exposed to high levels of pesticides in addition to endocrine disrupting compounds, such as those found in flame-retardants, which are ubiquitous in manufactured products. In this study, researchers collected biological samples and looked at health outcomes such as growth, neurodevelopment, respiratory disease rates, ADHD, and IQ. The community is predominately Spanish speaking and low-income, with many participants working or having family members working in the affected agricultural fields.

Study 3 is a study of chemical exposure in pregnant women and newborn infants that tested for the presence of metals, perfluorinated compounds (PFCs), and phenols in biological samples. Pregnant women in their third trimester delivering in a city in a western state were recruited to participate in the study. Samples were collected from maternal and umbilical cord blood and urine of mother-infant pairs and pregnant women. Approximately 100 women participated in the original study, with 16 completing follow-up interviews.

For Study 4, more than 400 children from the ages of six to eight were recruited to look at environmental factors related to development and the onset of puberty. Roughly, one-quarter of participants were Hispanic, one-quarter were Black, and more than a third were White. Serum and urine samples were tested for phthalates, PFOA, brominated flame retardants, bisphenol A (BPA), and other compounds. We completed 15 interviews with Study 4 participants.

A group of more than two-dozen volunteers, ranging from lay to expert researchers, institutional review board members, and participants in other biomonitoring projects, were recruited with Study 5 to be tested for the presence of Bisphenol A (BPA), phthalates, and polybrominated diphenyl ethers (PBDEs), which represent a set of chemicals commonly found in household and personal care products. Twenty-two of these participants were interviewed for our study.

Finally, Study 6 looked for the presence of contaminants that may have originated from nearby mining operations in a rural community in a western state. More than two-dozen households with at least one child between the ages of one to eleven years and that were located near a superfund site were recruited and 14 completed follow-up interviews. Environmental (water, yard soil, and household dust) and biological samples (urine, toenails, and blood) were taken and tested for aluminum, arsenic, beryllium, cadmium, chromium, nickel, and lead.

For each study, participants were randomly sampled with a target of 20–25 interviews that were representative of the overall study sample. Interviews were transcribed and coded in NVivo (QSR International Pty Ltd., 2012). Using an analytic induction approach (Lofland et al., 2005), we examined transcripts for elements of what we initially framed very broadly as "research altruism," a concept that we formulated as we previously analyzed our team's two studies. In that earlier work, we learned that people avidly agreed to participate even if it involved much time commitment and some degree of burden. With access to the other six studies, we continued that approach, and continually developed more focused codes that allowed us to break down types of research altruism. In continuing to elaborate on and rework our themes, we realized that we needed the more general concept of banal altruism to encapsulate research altruism.

4. Findings

While there are many factors that influence why a person chooses to participate in a research study, for the purposes of this paper, we were particularly interested in focusing on altruistic motivations. Through our coding and analysis, we developed three broad themes around the motivation to participate in research. We have coded these as participating as a means to contribute to some generalized group—a common humanity—that the individual feels a connection with; participating to contribute to science, which the individual sees as offering a general social benefit through knowledge sharing; and participating as a means to support the community-based organization partner, which the participant sees as contributing to a general social good within the community.

4.1 Connection to Common Humanity

Participants frequently commented that their involvement in research was motivated by their concern for other groups and their hope that those groups would somehow benefit from the research. Participants described their engagement as "we were really doing it from the societal benefit standpoint" (Study 4, P07) and "because it is good for everyone" (CCHES, P4166). From participant responses, it was clear that they believed that their involvement in scientific research contributed to positive social benefits. Additionally, though, their

descriptions about direct benefits were vague and operated over an unspecified duration of time.

Groups suggested to benefit from the research ranged from populations intimate to the participant to groups as general as society as a whole, a "general help-the-world kind of thing" (Study 4, P09). Those concerned about groups intimate to the participant often mentioned the potential of benefits for their children or other people's children, who they felt a connection with because of their experience as parents: "we were doing it because of our children. Because we both have girls and we felt like we can't not do this. We have to do this…for the future" (Study 5, P03).

While participants in different study types focused on populations that were most relevant to the research projects, e.g. women for studies on breast cancer and maternal health and neighborhoods for studies focusing on fenceline communities, the potential of benefits were often mentioned as future and not immediate. As one woman said, "well I just felt that breast cancer is so prominent, that it's…the more we can find out about it the better for my own daughters and everybody else in the future" (CCHES, P1814). While benefits could come in the form of having new knowledge to change current practices and behaviors, for others the return on potential benefits was very long term, specifically, intergenerational: "So, then I had two daughters, and I've always wondered and been interested in the notion of environmental toxins, how they interplay with genetics, and whether that was a factor in me getting cancer, and what does this portend for my daughters' generation" (Study 4, P04).

In addition to potential benefits being deferred, the exact nature of those benefits was vague. Participants alluded towards an imagined benefit was abstract and unspecified. One participant suggested that even if no specific hazards were uncovered in the study, having baseline data could be useful at a later date, presumably after some unforeseen change in knowledge of environmental risk factors (NCHES, P09). Participants generally stated that they engaged in research, "for the good of the community!" (NCHES, P47) and "mainly to help other people or help the future residents of this area" (NCHES, P29), without clarifying how the research would directly benefit those populations.

Several individuals characterized their decision to participate in research from a frame of social obligation, consistent with the understanding of a shared norm for behavior. A general feeling among participants was one of "somebody's got to do it…[so] why not me?" (Study 5, P08). They described this norm as part of what one does as "a good citizen" (Study 4, P02) and they thought that participating in research was "kind of your civic duty" (Study 4, P11). One parent used the experience of participating in research to teach her daughter about this social expectation. She said participating in research was a way "to give [of] ourselves and [to] our community" (Study 4, P14). This parent explicitly saw this as a behavior consistent with American values and used the discussion as an opportunity to teach about the United States. This sentiment was shared by another man who, struggling with health problems and advanced age, saw the research as a way to do his part, which he felt was important because he had not served his country in the military during wartime (Study 5, P10).

Finally, participants also expressed a mundaneness to their involvement in the study. They characterized their decision to agree to be in the study as casual and something that was unexceptional. One participant described this sentiment as "I've got nothing better to do" (NCHES, P37) and another said "I was in the neighborhood" (NCHES, P09), suggesting that their involvement in the specific study was more of a coincidence than a sacrifice.

Overall, participants generally felt that that participating in research was a way to contribute to a positive social good but that benefit is deferred over time. Who benefits directly and how they benefit are unclear. Time was often conceived of not in terms of days or years but rather in terms of generations. Feelings about participating in research were consistent with a sense of a shared moral obligation, with that obligation tied to notions of being a good citizen and doing one's civic duty. The decision to be involved in research was expressed as one that was not a significant personal sacrifice, but rather as "just" what any good person would do.

4.2 Connection to Science

For some individuals, motivation to participate in a research study was tied to their sense of connection to science, whether that was through a personal relationship to research processes or through generally valuing the knowledge products of science. Participants hoped that the knowledge produced by the study would have some benefit for others. One participant said, "if I can help to have a test to prove something for somebody else, why I'd be willing to do it" (Study 1, P04). In being involved in the research studies, participants communicated that scientific research was trusted as a key way of bringing about new knowledge. One participant emphasized, "we are believers in scientific research" (Study 4, P14).

Knowledge gained from the study may be viewed as valuable because of the aims of the specific research study, as one participant said "I thought it would be really helpful for medicine or the medical field" (Study 4, P05) and another stated "I wanted to further the cause of research into those issues" (Study 4, P04). Others saw knowledge more broadly, saying "to some extent, all information is good information" (Study 1, P05) and "I think, you know, the collection of aggregate information is always useful" (Study 5, P19). Participants saw value in research beyond the direct context of the study in how it contributed to "basic science to understand something new" (Study 4, P12).

One's personal connection to science, either through identifying as a scientist or having close relationships with scientists, supported some individuals' desires to be involved with the research studies. One participant, an epidemiologist, stated, "it's not appropriate for me to expect it of others if I'm not willing to do it myself" (Study 4, P07). This respondent felt that participation in the study was a way of "giving back to the community as researchers." This sense of obligation to the community of researchers was shared by another who said, "because I am a researcher and I understand the importance of participation so whenever I can and it seems relevant and appropriate I will participate even with phone surveys" (Study 5, P13).

For others, participation was motivated not by a professional obligation but out of respect for friends and family who work in scientific fields (e.g. "all my family are scientists" (Study 5, P02)) or for the scientists themselves (e.g. "I decided to participate because I thought it would be helpful… to people doing the study" (Study 5, P14)). One person noted they participated because they had "a friend who is a public health [professional]" (Study 5, P03). The friend introduced the participant to the study who then felt, "I would like to contribute to something…like that."

In considering participation in research, many described feeling that the research needed people and, since they could participate, they decided to contribute. Participants characterized their involvement in ordinary and unexceptional ways. One participant stated simply that the study "needed participants" (Study 1, P10) and so they agreed to participate. Another said, "it was mainly me just wanting to contribute to the research as I could" (Study 5, P13). With a sense that "they need to get participants somehow" (Study 4, P02), participants conveyed that they saw their personal sacrifice as minimal and worthwhile given what it offered to the research project (Study 4, P07).

Participants who noted the significance of science in impacting their decision to participate in the research studies generally stated either that they cared about the knowledge being produced or the researchers doing the study. Some participants characterized knowledge as the social good that comes from research while others saw the social good as being helpful to the process of science. Particularly for those who expressed a personal connection to science through being a researcher or having people close to them who did research, there was a sense of a shared obligation to participate in research. This obligation to participate in research, though, was again expressed through engagement in banal ways. Participants did not describe their participation as overly burdensome but instead as an option that was available to them that they did not perceive as requiring a great deal of them.

4.3 Connection to Community Organizations

Within our context of research studies that emphasized community-centered research, multiple participants highlighted the importance of the community organization in their decision to participate in the research study. For several participants, the fact that the community partner was working on issues that the participant cared about (Study 5, P16) or that could positively impact the community that they live in (Study 6, P11) encouraged them to participate in the research. Some participants based this assessment on an awareness of the work the organization was doing in the community, saying "I already know about Communities for Better Environment; any work that you do I think would be good work" (NCHES, P05) and "I admire the work that [Silent Spring was] doing and I wanted to participate" (CCHES, P522). Others were not directly familiar with the work of the community partner organization but made an assumption that the organization does good work based on first impressions. For example, one participant said, "well, instantly, I think I agreed because anybody who would name their group Silent Spring would show a connection with the environment and Rachel Carson" (CCHES, P31).

Some participants reported that they decided to be involved with the research project because they already or previously were involved with the community organization

(CCHES, P184; NCHES, P39). Because of this involvement with the organization, they had a sense of obligation to participate. One participant said, "I mean because I had been involved in the coalition that we were working with already, for quite a while…So when they asked me…I figured I should be a willing participant myself" (Study 5, P06).

In other cases, while not directly involved with the organization, some participants saw the research that the community based organization was involved with as supporting other work that the individual was already engaged with in the community. One participant described the research as helping to support a process of visualizing toxics, which she was already attempting to do through art (NCHES, P15). Others were involved with similar efforts led by other organizations. One participant said "at the time I was working at an environmental justice organization that focused on community-based participatory research" (Study 5, P11) while another explained:

> [My] organization, was involved in environmental health concerns and how it relates to onset of neurological problems or mental health problems. And we were part of a consortium with other organizations involved. Since we were involved in disseminating information about neurotoxic agents and its effects on human beings, I thought it would be appropriate to participate (Study 5, P15).

These individuals expressed not a sense of obligation to the organization, specifically, but to the issues that the organization was working on.

Engagement with the community organizations, explicitly, and the research team (i.e. the academic researchers alongside the community partners), more generally, provided motivation for some to participate in studies. Not only did the community organization support efforts in the community that participants cared about but they also helped to establish trust and legitimacy for participants. One participant said, "I knew the study PIs well through our work. So number one was that trust. So when they asked me to participate I didn't think much of it because I was like 'well, I know these people really well and this sounds interesting'" (Study 5, P11). Another said, "there can't be anything but good that would come out of that given that I trusted [the research team] and the structure." (Study 4, P09).

For those that felt that the community organization was an important factor, trust in relationships with the organization helped to make the decision to participate in the study an easy one. Just being friends with or knowing someone in the organization was enough for some: "my friend…who was working with that group, she said 'hey, ya wanna do this study?' And I said 'sure'. So that's it" (Study 5, P05). Others shared this sentiment that simply because a friend with the research group made a request of them, they were willing to be involved (NCHES, P23; NCHES, P35). One participant noted, "I knew the environmental activists here in the state and they were the ones that asked me to participate. So because I knew them and had worked with them in the past, I decided I would take part" (Study 5, P12). Based on their connection and trust with the organization, participants were able to see the demands of the study as nominal.

One's sense of connection to the community-partner organization was an important factor for many participants in the research studies. In particular, participants either knew or perceived that the work of the organization contributed to positive social benefits. Some worked directly with the organization and as such felt that this established an obligation to participate in the studies. Others felt an obligation to the work that they organization did, often through parallel efforts that they did with other organizations or in their own activism. Importantly, community-partner organizations engendered a sense of trust between participants and the research teams. With this trust established, participants saw their decision to be involved with the studies as an easy one to make.

5. Discussion

Through our analyses we found that many participants felt motivated to be involved with the research studies because they felt that the studies contributed to a broad social benefit. Because they held the belief that the work would lead to social gains, participants felt a sense of obligation to be part of helping to make those positive benefits for society come about. Importantly, they did not characterize their involvement as being hugely demanding of them. Rather, they described a feeling that their decision to participate was easy and relatively minor. There was some variation in how participants characterized their motivation based on whether they attributed it as related to a sense of connection to common humanity, a sense of connection to science and the research process, or a sense of connection to the community based organization.

While participants frequently reported how they hoped that the research would do some good for some group of people, they rarely characterized that hope in terms of how they might personally be perceived. Rather, their hope for goodness came from a sense of connection with and empathy towards others, consistent with Monroe (1996). When participants expressed a connection to society at-large, the specific benefits of the research were also general and vague. In particular, many spoke of impacts that would be distributed over time, perhaps for future generations. When participants expressed a sense of connection to science, they conveyed that they saw knowledge as the specific gain from the research. Knowledge to them could contribute to specific changes in behaviors or policies or it could be valued simply on its own, i.e. knowledge for knowledge's sake. Those who communicated that their participation was a result of their relationship with the community organization indicated that the benefits that they saw arising were for the communities that the organizations worked in. Typically, these communities were geographic communities, e.g. neighborhoods, but in other cases they were communities of affected groups, such as women of childbearing age. Consistently, participants expressed that their involvement in research arose out of their desire to bring positive social gains for social groups for which the participant expressed concern.

The concern that participants felt for the communities with which they had an affinity fostered a sense of obligation to participate in the research studies. This was not conveyed as a compulsion and no participants indicated that they felt that the decision to participate was a difficult one or that they felt coerced. Rather, their responses were consistent with a sense of a shared moral norm for behavior as described by Bykov (2016). This shared norm was

most clearly voiced by those expressing a connection to society most broadly. Several communicated how their participation was part of being a good (American) citizen. Their sense of civic responsibility included research participation as a moral norm for positively contributing to society. Others expressed a professional obligation to the research community. This is meaningful as scientists are trained to be skeptical and it is not automatic that all scientists would hold this sense of obligation. Like researchers, volunteers with the community organizations or organizations working on similar topics felt compelled to participate based upon their connection to the community organization and the work that the organization does.

Throughout responses regarding motivation to participate in the studies, participants conveyed that they felt that they did not make a large personal sacrifice to be involved. Importantly, we note that the idea that engaging in research is not a great personal sacrifice is a sentiment expressed by participants when they described altruistic motivations. That is not to say that participation in research is not burdensome or even was not burdensome for these participants. Rather, we see this as a facet of altruism, wherein participants may feel that expressing the degree of personal cost could negate some of their generosity in doing good. Generally, there was a sense that, because the work of the studies would contribute to some positive social benefit, participating in the study was just what any reasonable person would do. They expressed sentiments such as they happened to be available and eligible for the studies so they decided to participate. Participation for many was as simple as being asked by someone they trusted who was with the research team. Because of that trust, participants were able to conceive of their contribution as an easy one to make.

While other types of altruism expressed in the literature have parallels to the altruism that participants in the studies showed, we feel that these other concepts insufficiently capture the type of altruism observed in our analyses. While participants did express they were concerned about bringing about positive social change and doing the kinds of things that 'good people' do, unlike a strict notion of vernacular altruism, we did not find this concern to be centered on an individual's psyche and their self-concept as a 'good person.' No one emphasized that being perceived as a 'good person' by others was something that they valued. Additionally, some participants did make the connection between the research and potential benefits for their children, as would be consistent with kin-selected altruism, but often this provided a mechanism through which the individual connected their family's experiences to those of other families. Typically, those expressing concerns for their children also discussed how they hoped that the research would benefit other children and future generations. Finally, in the case of those who identified themselves as researchers there was an indication of reciprocal altruism as they saw their participation as part of a professional obligation. This sense of obligation, however, did not come in the form of directly trading favors across research teams. Instead, there was a sentiment that participation in research was a broad benefit to the scientific community and as researchers there was a shared norm to participate when feasible.

Participants expressed a mundane obligation without compulsion to participate in the research studies. We observe this as a kind of disinterested love that operates through banal, everyday practices to bring good into society. In engaging in an institutional setting like a

research study, we argue that participants may view bureaucratic processes as working towards positive social outcomes. The most general form of this altruism, which we call *banal altruism*, that we observed was in the case of participants who saw their involvement in the studies as part of civic practices that contribute positively to society. We believe that this concept should be explored further in future research, perhaps in light of motivations to participate in alternative forms of national services like AmeriCorps.

Within the specific institutional context of participating in a research study, we observe characteristics unique to the research process. Our findings indicate that participants in community-centered research studies see the process of participating in science as one that positively impacts society through knowledge production. By engaging in mundane practices that contribute to a positive social benefit we see the participants engaging in banal altruism. The specific type of banal altruism that we observed we refer to as *research altruism*, where those who engage in this practice view research and knowledge production as positive social effects. For community-centered studies, community based organizations contributed an additional mediating factor of trust development between participants and the research team, allowing participants to see their involvement as reasonable.

Not all of the studies contributed equally to the development of the concept of research altruism, with Study 2 and Study 6 providing limited examples of participants expressing such sentiments. In understanding why this might be, we considered the specific context of those studies. The sample population for Study 2 is largely Spanish speaking, low-income, and lives and works near the pesticide contaminated agricultural fields. Participants in this study were generally limited in their elaboration on their motivation to participate in the study and stated that their decision was based on a desire to know what their family was being exposed to. We suggest that a reason why this population did not express sentiments of research altruism is because they were less experienced with scientific research processes and possibly did not hold the sentiment that science automatically contributes positively to society. Particularly for marginalized populations that have historically been exploited by research processes, it makes sense that such communities might not have a shared cultural sense that participating in science would lead to positive social outcomes.

Study 6 focuses on a proximate site of contamination, which is similar to Study 1. Multiple participants in Study 1 linked their reasons for participation to altruistic reasons while few in Study 6 offered similar motivations. One reason for this difference might be that the source of environmental contamination for Study 1 remained a current employer in the community while the source of contamination in Study 6 was no longer a community employer. It could be that research altruism offers a way of deflecting the benefits of participation away from individual study participants when engaging in a research study could be threatening to the source of employment and the community broadly. Where the source of contamination is not a current employer, there is less need to deflect the benefits of participation away from the individual participant. More work is necessary to explore these possibilities.

6. Conclusion

Sociological attention to altruism examines the factors that lead people to engage in selfless behavior that serves to bring some kind of benefit to someone other than the individual. While participation in research generally requires this sort of selflessness, there has been relatively little attention to unpacking this idea of altruism within the context of research. This is an oversight that misses important reasons why people participate in research and does not give proper attention to the multiplicity of motivations that all fall within the umbrella of altruism. We show that participants in community-centered research studies offer many indications that altruism was an important factor in their decision to be involved in research. While we do find parallels with forms of altruism described in the literature, we feel that insufficient attention has been given to mundane practices of altruism, which by their lack of exceptionalness are likely most common. We refer to this process of engaging in ordinary, bureaucratic processes to contribute positively to society as banal altruism, and the specific type of banal altruism expressed within research as research altruism.

As others have suggested (Williams et al., 2008), an appreciation for the role of altruism may be an important consideration regarding how participants are recruited particularly for community engaged research studies such as community-based participatory research, citizen science, and environmental justice projects. Because in these types of studies there are often few resources to compensate people for participation, altruism may be an important focus of recruitment and study design. Based on our previous work with report-back of research results, community members appear to be strongly motivated to participate in research studies when they feel that the knowledge gained from the research study is being shared back with the community and the study participants in a way that can lead to individual and societal benefits. Intentional attention to these factors by researchers engaged in these forms of research is recommended.

Our findings also give us a deeper awareness of the benefits of community-based participatory research. We see here how CBPR leads to research altruism, which leads to better recruitment and retention, more science democracy, and more environmental health literacy. If more CBPR researchers grasp the connection to research altruism, we expect greater success in their projects, while being able to convey to participants the hopeful stance of research altruism.

Future work

With the development of our new theoretical concept, many new questions arise that merit future exploration and development. Importantly, as we saw differences in our participants who were largely Spanish speaking, as a shared moral norm to do good through participating in research, how much does this vary across cultural experiences? While white, affluent communities with high trust in science may see participation in research as contributing to a social good, ethnic minority communities that have historically been exploited through scientific practice, either through simply being studied excessively or through cases of direct violence and experimentation, may not view contributing to science as promoting a social good. The variation of research altruism across cultural context merits deeper exploration. Additionally, for populations with limited access to healthcare, participation in research

studies could be viewed as a way to access health services that would otherwise be inaccessible. These groups may show relatively less research altruism than more affluent groups with better healthcare access. For individuals that are able to afford health care services, participation in research may be more abstract and connected to a sense of knowing and general social benefit. This suggests that further research on the variation of research altruism across income levels is warranted.

Acknowledgments

References

Altman RG, Morello-frosch R, Brody JG, Rudel R, Brown P, Averick M. Pollution Comes Home and Gets Personal: Women's Experience of Household Chemical Exposure. J. Health Soc. Behav. 2008; 49:417–435. [PubMed: 19181047]

Appelbaum PS, Lidz CW, Klitzman R. Voluntariness of Consent to Research: A Conceptual Model. Hastings Cent. Rep. 2009; 39:30–39. [PubMed: 19213193]

Arendt, H. Eichmann in Jerusalem: A Report on the Banality of Evil. Viking Press; New York: 1963.

Beskow LM, Namey EE, Cadigan RJ, Brazg T, Crouch J, Henderson GE, Michie M, Nelson DK, Tabor HK, Wilfond BS. Research Participants' Perspectives on Genotype-Driven Research Recruitment. J. Empir. Res. Hum. Res. Ethics An Int. J. 2011; 6:3–20.

Brooks RA, Newman PA, Duan N, Ortiz D. HIV vaccine trial preparedness among Spanish-speaking Latinos in the US. AIDS Care. 2007; 19:52–58. [PubMed: 17129857]

Brown P, Brody JG, Morello-Frosch R, Tovar J, Zota AR, Rudel RA. Measuring the success of community science: The Northern California household exposure study. Environ. Health Perspect. 2012; 120:326–331. DOI: 10.1289/ehp.1103734 [PubMed: 22147336]

Bykov A. Altruism: New perspectives of research on a classical theme in sociology of morality. Curr. Sociol. 2016; :1–17. DOI: 10.1177/0011392116657861

Chin LJ, Berenson JA, Klitzman RL. Typologies of Altruistic and Financial Motivations for Research Participation: A Qualitative Study of MSM in HIV Vaccine Trials. J. Empir. Res. Hum. Res. Ethics. 2016; 11:299–310. [PubMed: 28251864]

Dickert N, Grady C. What's the Price of a Research Subject? Approaches to Payment for Research Participation. N. Engl. J. Med. 1999; 341:198–203. [PubMed: 10403861]

Fisher JA. Expanding the frame of "voluntariness" in informed consent: structural coercion and the power of social and economic context. Kennedy Inst. Ethics J. 2013; 23:355–79. [PubMed: 24552076]

Grant RW, Sugarman J. Ethics in human subjects research: do incentives matter? J. Med. Philos. 2004; 29:717–38. [PubMed: 15590518]

Hanson BL, Faulkner SA, Brems C, Corey SL, Eldridge GD, Johnson ME. Key Stakeholders' Perceptions of Motivators for Research Participation Among Individuals Who Are Incarcerated. J. Empir. Res. Hum. Res. ethics. 2015; 10:360–367. [PubMed: 26283681]

Humphrey N. Varieties of altruism - and the common ground between them. Soc. Res. (New. York). 1997; 64:199–209.

Hunter J, Corcoran K, Leeder S. Appealing to Altruism is Not Enough: Motivators for Participating in Health Services Research. J. Empir. Res. Hum. Res. Ethics An Int. J. 2012; 7:84–90.

Kimberly MB, Hoehn KS, Feudtner C, Nelson RM, Schreiner M. Variation in Standards of Research Compensation and Child Assent Practices: A Comparison of 69 Institutional Review Board-Approved Informed Permission and Assent Forms for 3 Multicenter Pediatric Clinical Trials. Pediatrics. 2006; 117:1706–1711. [PubMed: 16651328]

Lofland, J., Snow, DA., Anderson, L., Lofland, LH. Analyzing Social Settings: A Guide to Qualitative Observation and Analysis. Wadsworth Publishing; Belmont, CA: 2005.

Monroe, KR. The Heart of Altruism: Perceptions of a Common Humanity. Princeton University Press; Princeton: 1996.

Neal SMA. Commitment to Altruism in Sociological Analysis: Paul Hanley Furfey Lecture. Sociol. Anal. 1982; 43:1–22.

Nelson RM, Beauchamp T, Miller VA, Reynolds W, Ittenbach RF, Luce MF. The Concept of Voluntary Consent. Am. J. Bioeth. 2011; 11:6–16.

Newman PA, Duan N, Roberts KJ, Seiden D, Rudy ET, Swendeman D, Popova S. HIV vaccine trial participation among ethnic minority communities: barriers, motivators, and implications for recruitment. J. Acquir. Immune Defic. Syndr. 2006; 42:210–217.

Oliner SP. Altruism: Antidote to Human Conflict. Humboldt J. Soc. Relat. 1991; 16:1–37.

Piliavin JA, Charng H. Altruism?: A Review of Recent Theory and Research. Annu. Rev. Sociol. 1990; 16:27–65.

QSR International Pty Ltd. NVivo qualitative data analysis software, Version 10 for Windows. 2012

Simmons RG. Presidential Address on Altruism and Sociology. Sociol. Q. 1991; 32:1–22.

Singer E, Couper MP. Do incentives exert undue influence on survey participation? Experimental evidence. J. Empir. Res. Hum. Res. ethics. 2008; 3:49–56.

Wexler MN. The Biology of Human Altruism. Soc. Sci. 1981; 56:195–203.

Williams B, Entwistle V, Haddow G, Wells M. Promoting research participation: Why not advertise altruism? Soc. Sci. Med. 2008; 66:1451–1456. [PubMed: 18222579]

Highlights

- Investigates intrinsic motivations for participating in community-centered research

- Explores how people engage in research to contribute to a broader social good

- Examines altruism through perceived mundane behaviors

- Contributes two new theoretical concepts: banal altruism and research altruism