

The Ethics of Participatory Action Research on Poverty

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This article is based on an international webinar entitled “The Ethics of Research on Poverty” that was held in April 2018 and was hosted by Stacy Randell-Shaheen, USA (director of the Adult Learning Center in Massachusetts; Bonita Bennett, South Africa (director of the District Six Museum in Cape Town); Donna Haig Friedman, USA (former director of the Center for Social Policy at UMass Boston); and Bruno Tardieu, France (director of the Joseph Wresinski International Centre, ATD Fourth World Movement–France). The article asserts that participatory action research (PAR) on poverty needs specific ethical guidelines in addition to the general ethical principles of PAR. Through the inputs of the four webinar presenters, it explores the ethical guidelines of carrying out PAR projects on poverty and reflects on the common dilemmas they face.

“Of comprehensive knowledge about poverty and social exclusion -- knowledge meant to inform, to explain, and to lead people to action -- academic research will never be more than one component among others. It is the information component, partially explanatory, and thus lifeless. It will remain lifeless as long as two other components of knowledge are missing. These two autonomous and complementary components, which will add life and meaning, are:

- the knowledge which the poor and excluded have, from their first-hand experience, of the twin realities of poverty and the surrounding world which imposes poverty on them; and*
- the knowledge of those who work among and with these victims in places of poverty and social exclusion.”*

Joseph Wresinski - “A Knowledge that Leads to Action”, UNESCO, 1980

“Community participation has become the norm; [...] Although that still makes many academics uncomfortable, people increasingly acknowledge that local, experiential or applied knowledge can enrich the quality and impact of investigations. The work is more responsive, socially relevant and connected to affected communities” (Willyard, Scudellari, & Nordling, 2018). This excerpt comes from one of the articles on participatory action research (PAR) published in a recent issue of the scientific journal *Nature*, entitled “Partners in science: The people who should benefit from research are increasingly shaping how it is done”.

The San people —an over-researched community in South Africa — having had enough of being used by researchers, recently created a code of ethics to be imposed on all researchers wanting to study their community (San people, 2017). Accordingly, they banned use of the derogatory term “Bushmen”, they demand authority over approving and reviewing research that involves their community, and they want real benefits from the experience, not just promises of potential benefits in the future.

The two points above indicate the vital importance of this topic in today’s world. The four presenters noted that the PAR approach is increasingly gaining legitimacy in the eyes of institutions and academics as an efficient and successful method for building knowledge.

The webinar grew out of a one-week symposium that celebrated the centenary of Joseph Wresinski (founder of the ATD Fourth World Movement). It was held in June 2017 in Cerisy (France) and was entitled “Rethinking Our World from the Perspective of Poverty — with Joseph Wresinski”. The participants drew from their own experiences with extreme poverty (either by living in extreme poverty or by being engaged with people most affected by poverty), and four of them organized the webinar to discuss ethical guidelines that they want to see applied to PAR projects on poverty.

According to Daniel Selener in the *Handbook of Action Research*, participatory research is a “process through which members of an oppressed group or community identify a problem, collect and analyse information, and act upon the problem in order to find solutions and to promote social and political transformation” (Bradbury & Reason, 2011, p. 1). Hence PAR “has not been just a quest for knowledge. It is also a transformation of individual attitudes and values (ibid, p.32). Extreme poverty has been defined by Joseph Wresinski as an “absence of one or more factors enabling individuals and families to assume basic responsibilities and to enjoy fundamental rights. [...] This lack of basic security leads to chronic poverty when it simultaneously affects several aspects of people’s lives, when it is prolonged and when it severely compromises people’s chances of regaining their rights and of reassuming their responsibilities in the foreseeable future” (Wresinski, 1987).

In this article, we posit that the ethics of PAR are not developed enough for research with people living in extreme poverty. First we’ll situate the ethical principles discussed in the webinar vis-à-vis the existing literature on PAR; then we’ll elaborate on some ethical principles that need to be specifically applied in PAR on poverty, as presented during the webinar.

I. Ethical principles to apply in PAR on poverty

The four webinar presenters come from different cultural, academic, and professional backgrounds and have all had experiences with people living in extreme poverty. Depending on where they work, they have faced different challenges. For instance, Friedman has had to fight against many forces that questioned participatory research as a valid knowledge-building approach, including external funding agencies with specific agendas and a preference for traditional scientific research methods, and university leaders with a competitive outlook and a top-down relation to power. Tardieu and the committee of ethics at the Joseph Wresinski International Centre have to make sure that external researchers' access to materials in the archives conforms with the centre's ethical principles. Shaheen has always sought to make the public respect the words, time, and potential of people in poverty. And Bennett continuously works to extend the role of the District Six Museum (which preserves the memory of the mixed, vibrant community that lived peacefully in this district before Apartheid) as an entity that not only gives a voice to the community, but also creates this voice with the community.

Elaborating on Existing Principles

The varying experiences that the webinar presenters have had with extreme poverty guided them in developing a common set of ethical principles to be applied in PAR on poverty. The presenters elaborated on some of those principles that can be found elsewhere in the literature on PAR.

The transformational aspect of PAR: The webinar presenters reinforced what is written in the literature about the need for researchers to lead transformational PAR.

Shaheen emphasized the importance of researchers taking the following question into account: How will your research make a lasting difference in the lives of people living in poverty, in the systems that oppress them, and in the policies that foster racism, sexism, classism, homophobia, etc? Researchers have to be both advocates and researchers, she said, because the damage done by poverty is too critical to ignore; researchers have a moral imperative to speak out, to use a part of their research to make a difference.

Bennett described the District Six Museum as a significant place for transformation, as it aims to bring about change in people's perceptions.

Subject/object: Another guideline found in both the literature and the webinar demands treating all participants in PAR as subjects and co-researchers, and not as objects.

Shaheen considers this guideline the most basic component of ethical PAR on poverty. She stressed the need to design research projects where participants are co-researchers as the experts on their own lives. Hence, there should be no "Other", no "Us" and "Them".

Bennett echoed Joseph Wresinski's cautions about using people as objects to verify or interpret research. She described how community members who were interviewed felt uncomfortable after journalists left as soon as they had the information they needed, without any discussion about what the stories were for or where they would be published.

Friedman considers that people most directly affected by poverty derive benefit from being engaged as co-researchers from start to finish. She enumerated key factors for successful PAR projects, among them a sense of shared ownership and joy; the strength the research gains when people with direct experience of poverty take on meaningful co-researcher roles and get appropriate recognition; and the embrace of the participatory method as a true collaboration that arises from recognition of each partner's role and provides opportunities of learning for all. The presenters all agreed with Bennett that successful research engagements originate with the integrity of the people involved.

Mutual respect: A third guideline figures in both the Handbook and the webinar, namely genuine respect for the process and for the ideas of each participant in the PAR. The four webinar hosts emphasized the need for mutual respect when working together on research. Bennett recommended moving the focus from what people do not have (a deficit model of research) to what they do have and what they bring new to the table. Friedman maintained that PAR also succeeds when each group of participants brings its own expertise, and when that expertise is respected and valued. Tardieu spoke of the respect demanded from researchers who work on the archives at the Joseph Wresinski International Centre. The code of ethics they have to sign puts great emphasis on respecting the dignity of the individual and the group.

Level of literacy: Shaheen raised another issue addressed in the literature: participants' level of literacy. The acknowledgement of the crucial role of language was a major step in the shaping of PAR. Shaheen highlighted the need to check the literacy level of consent forms when working with people who have lived or are living in extreme poverty. She gave the example of people with only four years of formal education who couldn't understand the consent forms they had to sign, and she stressed the need to check the literacy level of each participant. Researchers need to make sure they understand the community they're going into.

Introducing New Ideas

Because the ethical principles for PAR addressed in the Handbook of Action Research and elsewhere do not focus specifically on poverty research, the webinar presenters introduced some guidelines to be followed in research projects involving people living in poverty.

They discussed a significant challenge faced by people living in poverty: symbolic and epistemic violence, which occurs when a researcher perceives them as objects, preventing them from developing their own knowledge and understanding. Unlike physical or mental forms of violence that can be encountered in other PAR projects and that are more concrete,

symbolic violence tends to go unnoticed. It needs to be acknowledged and addressed in ethical guidelines.

For some of the guidelines already mentioned in the literature, the webinar delved into how they relate to research involving people living in poverty. For instance, concerning mutual respect between participants in PAR on poverty, Tardieu elaborated on the code of ethics that applies to all researchers working on the archives of the Joseph Wresinski International Centre. Apart from the ethical imperative to respect the dignity of the individual and the group, all researchers have to respect the right to privacy. Also, no research can be done on any archives without the prior consent of the people who entrusted the archives to the centre. Furthermore, the idea of rights is associated with the idea of respect. The code of ethics insists on the right to self-expression, which consists of checking the research against the interpretation of people in poverty themselves, because they have a deep understanding of their own story regardless of their situation.

Related to respect is the importance for researchers to take time to get to know the people they are working with. Shaheen highlighted the need for participants to feel secure. When conducting a research project with people who live in extreme poverty, a researcher needs to meet them where they're most comfortable, to go to their homes and visit them in their neighborhoods.

Choice of words: The presenters introduced ethical guidelines that cannot be found elsewhere in the literature on PAR, among them the importance of choosing the “right” language and words, which is closely related to the idea of symbolic violence. Shaheen explained how the choice of appropriate words — especially around people who live in extreme poverty and who might suffer from low self-esteem and repeated humiliations — can be central to the success of the PAR. As an example of the power of language, she cited a speech of Barack Obama's in which he described himself as coming from a “broken home” because it was a single-parent home.

Who is framing the question? Another important issue should be at the heart of PAR, along with genuine co-researching and shared ownership: the framing of the question. Just by asking the questions, researchers can dominate and orient the research, intentionally or not. When researchers ask questions that reflect their own perceptions but that fail to acknowledge the perceptions of people in poverty, they risk conducting research that ignores the needs of people in poverty. Friedman contends that researchers rarely know much about how poor people survive and so they rarely ask the important questions or listen deeply or establish meaningful partnerships. Solutions that are generated top-down can be harmful and disrupt the informal ways in which people support one another, whereas people living in extreme poverty could propose measures that lead to policy change. As Tardieu said, people in poverty also have questions that they need to formulate — sometimes the most powerful questions. He underlined the need to conduct basic research prior to advocacy. Researchers tend to think they know what has to be changed, but they have to make sure they address the right issues.

Bennett added that policy-makers should go to communities to learn about their different social phenomena, for instance social cohesion. Both researchers and policy-makers need to recognize that all knowledge doesn't come from books. Researchers should take the time to ask participants in PAR projects if they think there are other ways to communicate their input. As Bennett said, "It's nothing but immersing ourselves in where people are; it's actually not asking questions, but having conversations."

Tardieu remembered that Joseph Wresinski shed light on the same issue a few decades ago when he pointed out how unethical it is for researchers to impose questions on people living in extreme poverty, thereby hindering the efforts of those participants to formulate their own questions. In a speech at UNESCO in 1980, Wresinski said: "No one has the right, even in the name of science, to hinder another's effort [...] to develop a liberating outlook. [...] For it cannot be said too often that to hinder the poorest people by using them as informants — rather than encouraging them to develop their own thinking as a genuinely autonomous act — is to enslave them" (Wresinski, 1980).

Benefits greater than risks: The presenters agreed that PAR projects on poverty, just like on any other research topic, should ensure that participants experience fewer risks and greater benefits. Friedman spoke of the San people in South Africa, to whom researchers promised that they would ultimately benefit from policy changes resulting from the research instead of making sure they benefit directly from the research itself.

Shaheen added that benefits to participants should be not only moral in nature, but also monetary. PAR on poverty should not have any hidden costs to the participants, she said; it should not cost them anything. Also, participants should be paid for their time. When Shaheen was working on research for her master's degree, she paid participants in compensation for the time they were losing at work. Shaheen also insisted on the need to include sections on policy change and fiscal processes in research guidelines to make sure that people benefit from offering their time and participation. Any ethical dilemmas, she said, could be circumvented by classifying payment as a "stipend" rather than a "monetary reward"; the stipend is a recognition that the time of people in poverty is valuable, that their opinion matters, and that they matter as people.

What is at stake? Finally, there is the ethical imperative of ensuring that participants know what is at stake. Ethical guidelines for medical and behavioral research stipulate that participation should be voluntary. In contrast, guidelines on PAR do not demand that potential participants fully understand the goal of the research. Tardieu pointed out that the right for participants to know the goal of the research is included in the code of ethics of the Joseph Wresinski International Centre. Further, the goal of the research should be the liberation of people living in extreme poverty. Shaheen contended that researchers must also be advocates because the consequences of cumulative disadvantages are too harmful to ignore and researchers into poverty have a moral duty to make a difference. Tardieu added that neutrality, often claimed by scientists, can be obscene in front of extreme suffering. Therefore, the goal of the research cannot be mere knowledge; it has to be liberation.

As we have seen above, the webinar presenters paid due attention to the Handbook and delved further into some issues that arise with PAR on poverty and its ethical principles. If there has been insufficient reflection on the specific ethical guidelines for PAR projects conducted on poverty and with people living in extreme poverty, there has also been insufficient reflection on the risks and the negative outcomes if those guidelines aren't applied. The webinar hosts discussed some of the risks.

II. Risks related to the non-application of those ethical principles

Risk 1: Narratives without essential input. When participants in a PAR project on poverty are not real co-researchers, a narrative may be created about people in poverty that does not include their input, that won't give an accurate idea of what they endure, and that won't necessarily address their real needs. This happens too often and prevents us from fully understanding and seeing the harsh realities of a life in poverty.

Risk 2: Unintended symbolic violence. Many of the risks are linked to the epistemic and symbolic violence that can occur (usually unintentionally) in PAR on poverty and that often takes the form of violence to the thinking of people in poverty. Shaheen highlighted the importance of getting to know them and helping them feel comfortable enough to participate. Also, many people living in poverty have a high incidence of trauma, so researchers should be familiar with trauma-informed care. As an example, they should ask participants where they want to sit, because people who have been through trauma often want to sit closer to the door to feel more secure. This kind of approach is essential when doing PAR projects with people living in poverty.

Risk 3: "The soft bigotry of low expectations". People living in poverty are often denied opportunities because of low expectations. Shaheen said that if other people don't expect much from them — the children in particular — people in poverty can end up underperforming even though they are as capable as anyone else. For example, African American students drop out of school at disproportionate rates, often because of the low expectations that teachers and administrators have of them. Shaheen asked researchers to examine the expectations they have of people in poverty and to expect the best, because the researchers are going to learn a lot from the other people participating in the research.

Solutions: The webinar presenters discussed how to avoid those risks and how to help people in poverty express their thinking. Bennett explained that the District Six Museum gives the community members a platform through which their stories and voices can be heard. It resists the label given to the museum as an entity giving voice to the community, but rather establishes rigorous processes to take part in creating and amplifying the community's voice. The museum gives community members the right to remember and record the past in ways that make sense to them. Bennett added that this process was of crucial importance in the configuration of the “new” South Africa.

Bridging the divide: Tardieu considered how to bridge the divide between the stories of people in poverty and researchers’ interpretations of those stories. It is important to recognize this divide and the danger of interpreting other people’s stories. Researchers have to listen carefully and also to identify their own emotions (anger or sadness, for example). Then, they should be open to the tables being turned, to other people interpreting their stories. They should share their own thoughts and see how people in poverty react to them, because people in poverty also need an academic community where they build their knowledge together. This process is at the heart of the ATD Fourth World Movement “Merging Knowledge” approach.

In the context of PAR, violence against people in extreme poverty is usually symbolic and epistemic in nature and, unlike physical violence, tends to go unnoticed by positivist scientists. Hence, it can be challenging to carry out ethical PAR projects on poverty and with people living in poverty. Yet it's not impossible. The fact that PAR is increasingly gaining legitimacy in the eyes of academics, institutions, decision-makers, and research environments (for example, in the scientific journal Nature) shows that when the "right" conditions pertain, "successful", beneficial, and ethical PAR projects can take place.

This leads us to ask whether the specific ethical guidelines that should be applied to PAR on poverty could also be applied to PAR in other areas.

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