



CHAPTER 11

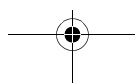
Using Participatory Action Research to Address Community Health Issues

Mary Brydon-Miller

Summary

What do students at a prestigious dance school, the people of Yellow Creek, Kentucky and women in rural Zimbabwe have in common? They have all taken an active role in research projects aimed at addressing specific health concerns facing their communities. In the case of the dance students, the health issue was body weight and shape preoccupation, a problem that can lead to bulimia and other eating disorders; in Yellow Creek it was environmental hazards; and for the women of Zimbabwe the concern was AIDS/HIV. The traditional image of the physician as the omniscient, concerned healer-of-all-ills is giving way to notions of health care as a long-term partnership emphasizing wellness and the management of chronic illness. But health research has, to a large extent, remained fixated on a belief in the exclusive power of experts to generate accurate and useful knowledge regarding medicine and health care.

This chapter will explore the ways in which participatory action research has been used as an alternative to traditional research in the areas of health and wellness. After defining participatory action research and briefly considering the theoretical and historical backgrounds of this practice, an examination of the variety of ways in which such research might be carried out will be provided. A discussion of specific studies that have used this approach in the area of health care will follow focusing on the examples noted above. We all have the power to take an active role in our own health care and in promoting wellness in our communities. Participatory action research provides a way for individuals to take part in the process of generating knowledge and advocating positive social change in order to promote more effective health care practices



as well as a more equitable distribution of health care services, both in the developed world and around the globe.

Definition and a Brief History of Participatory Action Research

Participatory action research combines aspects of popular education, community-based research, and social action. As the Figure 11.1 suggests, (Brydon-Miller 2001a) participatory action research is a collaborative process in which the researcher works with community members to identify an area of concern to that community, generate knowledge about the issue, and plan and carry out actions meant to address the issue in some substantive way. Traditionally, participatory action research has focused on working with groups that have been

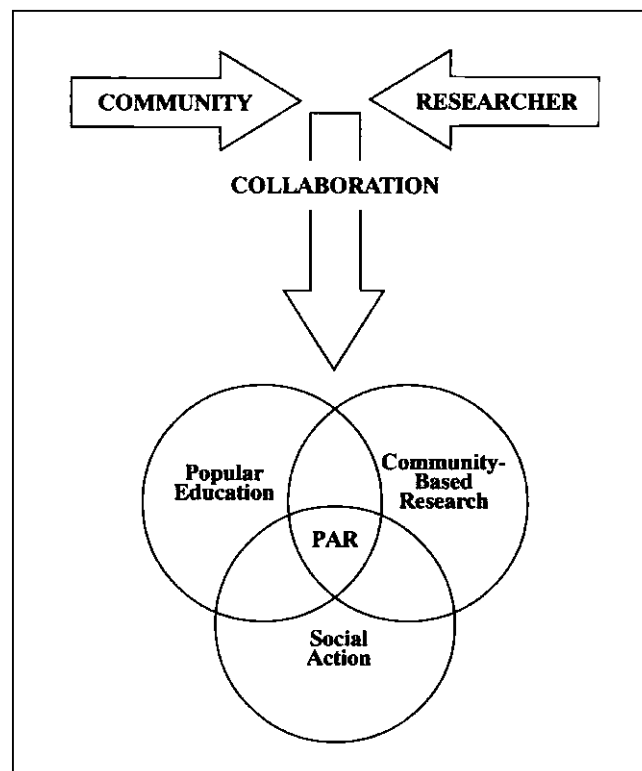


Figure 11.1 Reprinted with permission from Tolman, D. and Brydon-Miller, M. (2001) *From Subjects to Subjectives: a Handbook of Interpretive and Participatory Methods*. New York, NY: New York University Press.



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economically or politically marginalized or oppressed (Hall 1981). This reflects the roots of this practice within the developing world as well as its expressed commitment to working for positive social change. By emphasizing work within marginalized communities, participatory action research seeks to address the underlying causes of inequality while at the same time focusing on finding solutions to specific community concerns. Participatory action research is an iterative process, often beginning with community dialogue, it can then move to a phase in which some form of data are generated, leading to action, and from there back to dialogue. This action/reflection cycle allows participants to learn from their action and to then translate that learning into ever more sophisticated and effective forms of social action.

Beginning in the early 1970s researchers in Tanzania, Colombia, and India began to recognize and discuss the ability of ordinary people to take part in the process of knowledge generation (see Fals Borda 2001 for a more detailed historical review). These early efforts emphasized the importance of developing strategies that would allow people to take part in making decisions that affected their lives in significant ways. In Europe, North America and Australasia as well, researchers were challenging the notion that knowledge must be objective and value free. Instead they suggested that scientists must be passionately committed to the struggle for social change and that a part of this commitment involved finding ways in which the principles of democracy and citizen action might become a part of the research process. The work of the Highlander Research and Education Center in New Market, Tennessee (Lewis 2001) and the International Council for Adult Education in Toronto and the Institute of Development Studies at the University of Sussex (Hall 2001) as well as ongoing efforts by Reardon *et al.* (1993) in East St Louis (1993) provide examples of participatory action research focusing on a variety of communities and concerns. Through countless projects and collaborations, these centres and others like them have established their commitment to adult literacy and education, economic development and grassroots organizing, and to improving the health and well-being of individuals, families, and their communities across the country and around the world.

For many participatory action researchers the work of Brazilian educator and activist Freire (1970/1993) has been particularly influential in providing both an ethical foundation as well as practical examples of how to go about conducting such research. His notion of conscientization, the process of developing a critical understanding of the social, political, and economic forces which shape experience, underlies much of our work as participatory action researchers. In addition, his method of using the rich and nuanced knowledge already extant in communities as the source of his pedagogy and his insistence on understanding ourselves as co-learners establishes relationships with community members as equal partners in the research process. As Freire once observed, "Those promoting participatory action research believe that people have a universal right to participate in the production of knowledge which is a disciplined process of personal and social transformation" (1997: xi).



Theoretical Foundations of Participatory Action Research

Participatory action research, with its focus on social justice and its rejection of assumptions that research can or should be either objective or value neutral, was made possible by the critique of positivism provided by critical theory. Critical theorists, such as Habermas (1971), suggested that knowledge can take many forms and that no form of knowledge exists outside of the social, political, and economic contexts within which it was generated. The kind of technical expertise generally associated with science is one valid and important form of knowledge, but it is not the only way to understand ourselves and our world. We also know the world through our interactions and our relationships with others; this interpretive form of knowing has been the basis for much qualitative research.

Finally, and of most relevance to participatory action researchers, we know the world through our actions and through our attempts to change the material conditions of our lives. As early as the 1940s Lewin (1951), a well-known social psychologist, was suggesting much the same thing. When people come together to identify issues that concern them, when they gather information and discuss what they have learned, when they then take action based on this knowledge and reflect on that action in order to assess its effect and to determine their next steps they are generating what Habermas would call critical knowledge, a form of knowledge that supports the emancipatory interests of human beings. It is the generation of such critical knowledge that is the goal of participatory action research.

More recent participatory action researchers have looked to other theoretical frameworks, in particular feminist theory, to inform their work. As Maguire (2001) has noted, not only does feminist theory remind us of the critical role of gender in shaping social interactions and structures, it has also suggested that as researchers we must be aware of issues of oppression of all kinds and must continually challenge ourselves to find more effective ways to allow individuals and groups that have traditionally been silenced and often misrepresented by researchers the opportunity to speak and to advocate on their own behalf. More recent theoretical frameworks such as postcolonial and critical race theories which focus on issues of power, agency and representation offer new perspectives on the work of participatory action researchers (Bell 2001; Brydon-Miller 2001b; Williams and Brydon-Miller, 2004).

Participatory Action Research Methods

Participatory action researchers use a variety of methods, including both qualitative and quantitative approaches, in order to generate knowledge about important social issues. These methods are adapted for use in community settings and emphasize data gathering that will be useful and usable to all of those participating in the process. The sophisticated statistical analyses and costly



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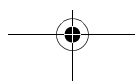
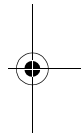
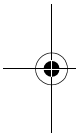
computer modelling that are the hallmarks of much current medical and epidemiological research are replaced with methods that are both comprehensible and affordable. Innovative methods drawing on art, theatre, storytelling and music have also been developed for use in community settings.

Quantitative approaches to participatory action research

The Yellow Creek project described in some detail later in this chapter is one example of the use of quantitative methods in participatory action research (Merrifield 1993). Another excellent example is the community-based survey conducted by workers at the East Side Village Health Worker Partnership of Detroit, Michigan, along with researchers from the University of Michigan (Schulz *et al.* 1998). This survey of 700 inner-city households focused on looking at the relationship between psychosocial and environmental stressors in women's lives and specific health outcomes for the women and their children. The survey was developed by a steering committee made up of representatives of local community-based organizations such as citizen action groups and community development organizations, staff from local health departments, and academic partners. Residents of the target neighbourhood were hired as interviewers because it was believed that they would be more effective in encouraging participation, better able to understand the issues facing respondents and to provide at least temporary employment opportunities in an area facing serious economic problems. Results of the survey have been disseminated to the community in a variety of ways in order to ensure that local residents have the opportunity to participate in the process of reviewing the data collected and developing action priorities based on this information. As the authors note, the process was both time-consuming and labour-intensive. It takes time to develop relationships of trust in communities that have little reason to assume that authorities will follow through on promises or act in the best interests of those without financial or political resources. It takes time to educate community participants about the research process and to work together to develop effective data gathering methods. On the other hand, processes that involve community members in framing the research questions, collecting and interpreting data, and determining the uses of the information in community change efforts, can both contribute to the scientific literature and to the social resources available to residents of disenfranchised communities (p. 22).

Qualitative Approaches to Participatory Action Research

Qualitative methods such as open-ended interviews, focus groups and ethnography have also been used as the basis for generating data in participatory action research projects. Using a method they refer to as "participant-focused research" or PFR, Flaskerud and Anderson (1999) describe one example of the use of



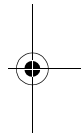
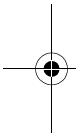


ethnographic methods in working with adolescents in a juvenile detention facility. Initial ethnographic data were generated through the use of participant observation, individual interviews and group discussions. These data were then reflected back to the adolescents who were able to confirm the ideas presented and the preliminary interpretations of the researcher. The results of this process were then used to develop content for health classes focused on issues identified by the youth themselves. This resulted in sessions dealing with topics from the treatment of acne and strategies for effective muscle-building to the prevention of sexually-transmitted disease. At the same time, the adolescents participating in the study expressed an interest in using their experience in order to help other teens to avoid the same problems that had led them to detention. Finally, the results of this research are being used to develop a risk reduction curriculum involving adolescents in all phases of planning, implementation and evaluation of the project.

Arts-based Approaches to Participatory Action Research

In an effort to maximize community involvement, participatory action researchers have developed a variety of innovative arts-based methods as well. As Budd Hall recently observed: outside the more formal strictures of the academy, knowledge is in fact created in a myriad of socially constructed and creative ways. Participatory research is among other things about the social construction of knowledge, the collective construction of knowledge. When looking for inspiration around methods of participatory research we need to take our clues from the creative and collectively constructed practices which abound in our societies and movements (2001: 174).

These methods serve both to record critical data about specific issues and to provide a focus for community dialogue. For example, Caroline Wang and her colleagues (1996) pioneered the use of photography as a data collection device in participatory action research. Photography has, almost since its inception, been used to record social disparities and to advocate on behalf of the oppressed. The images of photographers such as Jacob Riis, Lewis Hine, and Dorothea Lange documented the poverty, unsafe housing, and other social problems of their time in a way that still touches viewers today. But photovoice or photo novella puts the cameras in the hands of the people themselves, giving them the opportunity to tell their own stories in a way that transcends differences in education, social class and language. Wang *et al.* worked with women in rural China to document the health care needs within their communities. As the authors note, this method, "served not only as an information-gathering tool, but was also designed to create community and to empower participants to express their vision, literally and figuratively, to policymakers" (1996: 1395). This same process has been used to document the lives of refugee families in the United States (Brydon-Miller 2001b) and with rural Mayan women to examine issues such as work, health and illness, and the effects of war (Lykes 2001a,b).





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Lykes also describes the use of other creative arts such as storytelling, movement and dance, dramatizations, drawing, collage and mask-making in her work in Mayan communities.

Drama has been used by other participatory action researchers as a means of engaging communities in dialogue and of giving participants an opportunity to communicate their concerns to a broader audience (Lynd 1992). Using what they call “ethnodrama”, Mienczakowski and Morgan (2001) have developed performances dealing with issues such as attitudes toward schizophrenia, drug and alcohol treatment, and sexual assault. Beginning with ethnographic methods similar to those described above, the researchers gather detailed accounts from consumers, health care providers, and others. These accounts are then used to construct a dramatic performance in which these experiences are enacted, requiring the researchers to find a way to represent the multiple understandings and responses to complex issues and interactions. Following performances the audience is invited to discuss the material and their own experiences with the actors and other members of the creative staff. Performances are used as means of educating health care professionals about the perspectives of consumers, as well as to provide other audiences with an opportunity to gain insight into these difficult and compelling issues.

Social Action Approaches to Participatory Action Research

Perhaps the purest form of participatory action research, the approach which most directly addresses Habermas’ notion of the emancipatory interests of humankind, is in the generation of knowledge through direct social action. Of course, all participatory action research by definition involves some attempt to achieve positive social change. But these actions in and of themselves can provide an important source of knowledge. Individuals with physical disabilities who successfully challenged the owners of a local mall on their failure to provide access and, in so doing, created a state Supreme Court precedent on architectural accessibility provide an example of this type of participatory action research (Brydon-Miller 1993). In another example, women in rural India, who originally organized around the issue of domestic violence following the dowry-related death of a young woman in their community, continued to work together to develop educational opportunities for girls and women and health care for their village (Auluck-Wilson 1995). And in a third case, Yeich (1996) describes how, in her work with homeless people in Lansing, Michigan, participants engaged in a variety of actions including organizing demonstrations, testifying at hearings, and working with the media. She notes that no two participatory action research projects will look the same, because communities and the issues they face all take on different and distinct dimensions. However, she goes on to observe that, “The only guideline that is universal to all organizing projects is the need to encourage the leadership and decision making of group members. This is



the heart of grassroots organizing. It is PR's unrelenting focus on this principle that makes it a useful approach" (p. 120).

Applications of Theory and Methods of Participatory Action Research

The three examples referred to in the opening of this chapter serve as good models for the variety of health issues that participatory action researchers have addressed, as well as providing a sense of the range of methods that are available to researchers using this approach. We will examine each of these studies in some depth and consider the implications of this work for future research in the field of health psychology.

Dance Students Confront Issues with Body Weight and Shape Preoccupation

Piran (2001) used her long-term involvement with a co-educational, residential dance school as the basis for her participatory action research project. Asked to work with students and staff at the school to address concerns regarding body weight and shape preoccupation, Piran involved the students in focus group discussions that allowed them to explore together their attitudes toward their bodies and the forces that influence this relationship. In discussing these concerns, the students became aware of the pressures they encountered within the school environment, and within society as a whole, which provoked body weight and shape preoccupation and in some cases led to more serious problems with anorexia, bulimia, and other eating disorders. Piran's ten-year relationship with the school allowed her to witness dramatic changes in the culture within the school as she describes in her account of one of the focus group meetings. In this meeting a group of first-year high school students, some new to the programme, some veterans, were discussing attitudes toward body image when one of the new students made a comment about "fat chicks". This led some of the veteran students to challenge her use of such derogatory terminology and to consider what characteristics were really central to being a talented dancer. As one student observed, "You can express your feelings no matter what your actual weight is. We have a right to be who we are. I don't want to change my body" (p. 232).

In addition to achieving a more mature and nuanced understanding of the way in which their bodies were being objectified and used to control their behaviour, the young women also engaged in a number of actions which altered school policies and procedures in fundamental ways. For example, they challenged their male partners who complained about the weight of the female students as a way of excusing their own inability to perform adequately in a pas-de-deux class. In this way they were able to convince the school to institute safety



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training for male dancers before they began these classes and to convince their male partners that both parties must take responsibility in such situations.

In one particularly telling incident, Piran describes an “emergency” focus group meeting called by the girls themselves after they had been teasing one of the other female students for being a “butch”. As they discussed their behaviour they came to realize that they had been jealous of the young woman’s athleticism and physical power. When one of the girls suggested that “girls can’t have too much power”, they were struck by the implications of their own prejudices and determined to apologize as a group to the student they had teased.

Piran’s work points to the importance of establishing a long-term commitment to the community with which you are working. Participatory action research requires that the researcher establish a genuine rapport with the people involved in the project, that she have respect for these individuals and their ability to take an active and informed role in creating change. This recognition of the power of community participants then allows for a shift in control of the project to take place, from the academic researcher to members of the community itself, as Piran’s work demonstrates. It is this shift which makes it possible for such collaborations to achieve fundamental change in the way in which individuals and institutions understand and address issues which concern them and provides them with the skills and resources necessary to maintain these changes over time.

Appalachian Activists Study Water Pollution and Health

Since it was founded in the early 1930s, the Highlander Researcher and Education Center in New Market Tennessee has provided the opportunity for citizen’s groups of all kinds to come together and to gain the knowledge and skills necessary to effect social change in their communities. Highlander played a pivotal role in early labour organizing and the civil rights movement, led efforts on land reform, and was the site of much of the early participatory action research to take place in the United States (Lewis 2001).

One area of particular interest at Highlander has been environmental health. Merrifield (1993) describes the efforts of one group of activists from Yellow Creek, Kentucky, who were concerned about the possible effects of chromium and other toxins that had polluted the local drinking water. With support from students and faculty from Vanderbilt University, this group conducted a health survey of nearly three hundred households along the creek. The results of this survey showed increased levels of kidney and gastrointestinal problems as well as an elevated risk of miscarriage. Not only was the process successful in identifying specific health problems, but as Merrifield notes, the survey gave them a reason and an incentive to call at every household along the fourteen-mile length of the creek, and sit down and discuss with them the problems they were experiencing. Without the survey they might not have found the time and energy to do this. Second, it broadened and strengthened the leadership within the group. The prime activists in the health survey were women who



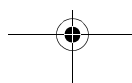
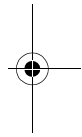
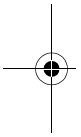
became better informed and more vocal and confident through their work with the survey. And finally, the process of doing the survey enabled the group to draw on and mobilize new outside resources (p. 78).

One of the goals of participatory action research, reflected in the experience of the Yellow Creek community, is to develop the capacity of citizens to understand and develop solutions to their own problems rather than relying on outside experts to do this on their behalf. One shortcoming of this project, according to Merrifield, was in the reliance on others, in this case students from Vanderbilt University, to analyse the data generated in the survey which took time and shifted ownership of the process away from the community itself. Even so, this project demonstrates that community groups can use quantitative methods in order to generate data that will be taken seriously by authorities. This often requires some support by those trained in such methods which can lead to tensions such as Merrifield describes around issues of ownership and use of the data. Nonetheless it can be a powerful tool for community groups, especially when they are dealing with situations such as this in which the case is most compellingly made by the use of quantitative data. Negotiating effective relationships between community groups and those with the requisite technical skill requires an open dialogue regarding issues of ownership, control and representation.

Merrifield describes another project supported by Highlander staff in which citizens stopped a local landfill from operating after it was discovered that hazardous materials had been improperly disposed of at the site. Here local activists learned to identify which chemicals had been transported to the site, and to research the possible health effects of exposure to these substances. Merrifield describes what happened when the group finally had the opportunity to meet with an official from the health department.

In a standard technique, he reeled off a list of chemicals with long names which had been found in the samples from the well, then hastened to assure the citizens that these chemicals were harmless. They pulled out their copy of a chemical directory which we had given them, looked up the names of the chemicals, and challenged the inspector. "This book says this chemical may cause liver damage, that one affects the central nervous system." The inspector left speedily, and the citizens, while disturbed by the nature of the information they had found, felt empowered to have been able to challenge an "expert" on his own ground (pp. 80–81).

Merrifield does not suggest that scientific knowledge is invalid, but rather that science must be accessible and accountable to ordinary people. Such examples demonstrate that this is indeed possible and that such efforts can have a profound effect on the individuals involved and on the communities in which they and their families live. They also make clear the ability of community participants to acquire a sophisticated and nuanced understanding of complex issues and to use this knowledge to further their own agenda for social change. Finally, these projects and others like them demonstrate the power of community-building





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to provide ordinary people with the information and resources necessary to address issues once thought to be the purview of experts alone.

Using Participatory Diagramming to Understand AIDS Transmission in Zimbabwe

Perhaps the health issue most frequently addressed by participatory action researchers has been the area of AIDS education and prevention. As studies in the United States (Stevens and Hall 1998; Anderson *et al.* 2001), Canada (Lindsey and Stajduhar 1998; Roy and Cain 2001), Scotland (Huby 1997), Ghana (Mill 2001), Thailand (Jirapaet 2000), and Indonesia (Moeliono *et al.* 1998) indicate, the use of participatory methods among practitioners in this area has been widespread. The final example to be described here deals with the use of what the author calls “participatory diagramming” to facilitate discussion of safer sexual practices among women in rural Zimbabwe. Noting the difficulty these women sometimes encounter in engaging in open discussion of current sexual practices, Kesby (2000) demonstrates how the use of diagramming can provide a more effective means of identifying key behaviours and interactions in the development of practices less likely to result in the transmission of HIV/AIDS.

The project was based on the work of two focus groups of ten women each, one drawn from participants already active in a local HIV/AIDS peer education group, the other group drawn from a farming community and made up of friends and relations of a key informant with whom the author had worked in the past. The groups met two or three times for several hours of intensive discussion. Using inexpensive and readily available materials such as index cards, string, and stones, the women were asked to consider a number of issues related to HIV/AIDS transmission and sexual decision making. In a laudable effort to “avoid abuse of the term ‘participatory’”, the author describes the study as an example of what Cornwall and Jewkes (1995) would term “shallow” participation, “in the sense that the principal researcher maintained control over the research agenda and process.” (Kesby 2000: 1726). That notwithstanding, the study is an excellent example of the way in which innovative methods readily available to community members can be used to generate knowledge and to guide planning for both individual and collective action.

The themes raised in the focus groups included the women’s basic understanding of HIV and AIDS, the context of sexual decision making, and the identification of future goals for sexual health. Specific questions related to each theme were used to generate discussion with participants being asked to write down key words on cards and then arrange the cards into diagrams indicating the way in which the various ideas related to one another. Thus “risk of catching AIDS” was related to other issues such as “dislike of condoms”, “ignorance” and “STDs” on one group’s chart and to “having too many partners”, “married women have no option to use condoms” and “lack of information” on the



other group's. These terms are then related to other ideas to form complex flow charts which illustrate the many factors influencing aspects of HIV/AIDS infection. The author is explicit in stating that "analysis cannot be based on (idealised) western models of sexual behaviour", further noting that "condemnation of contemporary men's multiple partnering and liaisons with commercial sex workers risks ignoring the historical development of these practices and their roots in colonial male labour migrancy and the dehumanising conditions of all-male hostels" (p. 1724), the legacy of Zimbabwe's colonial past. On the other hand, as he goes on to suggest, "cultural sensitivity does not imply that existing behaviour is beyond challenge", especially not when the consequences of the behaviour have had such devastating effects on individuals, their families and communities. Finding this balance between cultural sensitivity and a respect for the historical, political and economic forces that shape behaviour on the one hand, and a commitment to promoting positive social change on the other, is a major challenge to participatory action researchers working outside of their own cultural and social contexts and requires continued vigilance, self-reflection and dialogue with community members.

This final example demonstrates the potential for creative methods to begin to address the seemingly intractable problems facing poor communities around the world and the importance of exploring alternative means of generating community understanding and control of issues. Research methods must be adapted to address the needs of local communities and to take advantage of the existing skills and resources of local peoples. Finally, it points to the importance of addressing both the immediate needs of communities, while at the same time engaging in a collaborative exploration of the broader social and economic inequalities which create and maintain these problems.

Continuing Challenges in Conducting Participatory Action Research

"In practice, participatory research rarely follows the smooth pathway implied by theoretical writing" (Cornwall and Jewkes 1995: 1672). First of all there are the everyday challenges of working with a group of people who bring to the project their own differences of opinion, their own ways of interacting with one another, not to mention the constant demands on their time and energy that make devoting additional effort to community problem-solving so difficult. Most often the participatory action researcher is an outsider, someone who is at least initially unfamiliar with the various stakeholders in the community, making it all too easy to get side tracked by the demands of the loudest or most organized factions within a community. Many communities have had experience with outside researchers before, and most often these experiences have not been positive. The researcher may have been happy with the results, more publications and grant money, but what did the community gain through their involvement?



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Chataway (2001) discusses her experiences working in the Native community of Kahnawake with particular candour. Factionalism within the community, combined with a suspicion of outsiders well justified by past history, created tension around the research process. Chataway notes one session in which a local leader with whom she had met and talked extensively stood up in the public meeting and said, "You white people think you can just come in here for half an hour, take what you want, and leave" (p. 249). The author describes her own anger and indignation on hearing this accusation levelled at her after months of work within the community. I faced a similar experience myself when, after more than two years of working within the disabled community, a fellow participant and friend read a draft of my work and accused me of taking advantage of the community to further my own interests (Brydon-Miller 1993).

These community responses, though perhaps not justified, are certainly understandable. It takes time to build trust, and often years of commitment before you begin to see any substantive change in the lives of the people with whom you are working. And there are sometimes setbacks as these examples suggest. In a sense we researchers have brought this distrust upon ourselves by our use of deception, our lack of real commitment to local issues, and our focus on our own careers over the pressing needs of the communities we claim to serve. The only remedy to this lack of trust is to renew our own commitment to working with community members in an egalitarian and open fashion in order to earn the trust we and other researchers have abused and lost in the past.

This brings up another dilemma that faces the participatory action researcher. When are you done? As Northway suggests, it is important for researchers "to work closely with their co-researchers to ensure that there is a common understanding of the extent of commitment that everyone is prepared to give and the level of commitment desired by others" (2000: 33). In Northway's research this negotiation was made particularly challenging because her co-researchers were individuals with learning disabilities for whom the process and opportunity for participation were new and for whom such relationships were particularly important. But in any case in which researchers enter into a community, encourage people to become involved, establish friendships and relationships of trust and mutual reliance, the process of completing the project must be approached with particular care.

In attempting to address some of the ethical issues that plague traditional research, participatory action researchers encounter a new set of challenges. No matter how committed the participatory action researcher might be to working with members of the community in an open and egalitarian manner, the realities of differences in power and privilege cannot be simply erased or set aside. Who speaks on behalf of the community? Whose interpretation of events is heard and whose silenced? Well-meaning academics may assume that they understand the issues facing the individuals and communities with whom they work, and believe that they can serve as effective advocates for these groups, but this presumption simply maintains the existing hierarchies which



have silenced poor and oppressed communities in the past. At the same time, it is important to recognize the broader political and economic forces that work to maintain such inequalities. (For a discussion of some of the theoretical and practical aspects of this issue see Williams and Brydon-Miller, 2004.) These differences in power and authority are exacerbated in areas such as health care in which practitioners have traditionally been treated with unquestioning respect and in which people believe they have no expertise or relevant experience on which to base their actions (Mason and Boutilier 1996; Hagey 1997; Stuart 1998). But as the examples discussed in this chapter have, I hope, made clear, it is in just such arenas that participatory action research can make the most difference in people's lives. The challenge for the participatory action researcher, then, is to remain mindful of the ever-present influences of power and privilege and to endeavour to bring these dynamics into dialogue with community members in an open and honest manner. In addition, researchers must use whatever power and authority they do possess to further the interests of the community and to see that their voices are heard.

Conclusion: A Call to Action

Participatory action research is always time-consuming, often frustrating and confusing, and sometimes not much seems to get accomplished. Nonetheless, after almost twenty years, I cannot imagine working in any other way. Why? Because I find it to be the research practice most consistent with my own values and belief system. I believe that people have the right to participate in the decisions that influence their lives and the lives of their families and communities. I respect people and their knowledge of their own experience and concerns. I enjoy spending time with people and coming to know them as individuals. I am practical. I like to solve problems, real problems and witness change taking place. And I like to have fun, it is not worth doing if you are not having fun. Does this describe you as well?

What health-related issues are of most concern to you and to members of your community? How can you take an active role in addressing these issues? This discussion of participatory action research provides examples (and I hope some inspiration) to those of you who would like to take and find ways of making a difference. I encourage you to find and read some of the studies discussed here. Contact organizations in your community that deal with problems you feel are important. Spend time volunteering. Offer your expertise and labour to support their efforts. Talk with your friends and other volunteers about the work you are doing. Try to understand why the problems you are dealing with have developed and what is keeping them from being solved. And let me know what you are doing. I would love to hear from you about your work and about how you have taken this discussion of participatory action research and adapted it to the issues of most concern to you and your own community. You have the power and the knowledge to make a real difference in the problems



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you see around you, you only have to make a commitment to working with others in order for change to happen.

Key Points

- People have the right to participate in decisions that affect their lives and the lives of their families and communities. This is especially imperative when basic issues of health and wellness are at stake.
- Participatory action research combines popular education, community-based research, and action for social change.
- Participatory action research focuses on working to promote social justice within communities that have been marginalized or exploited.

Assignment Questions

1. Describe an experience related to health or illness in which you felt that decisions were being made without your input or involvement. Compare this to a situation in which you felt in control of the process. What made these two situations different? How important is it to you to feel involved in such health-related decisions?
2. What are the most serious health care issues currently facing your community? How might a participatory action researcher go about addressing these concerns?

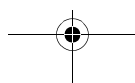
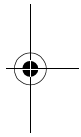
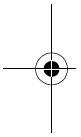
Further Readings

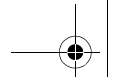
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