

Participatory action research to understand and reduce health disparities

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Participatory action research (PAR) is an excellent way to systematically learn about the conditions under which people experience health disparities, what it is like from the perspective of those experiencing such disparities and, even more importantly, how to ameliorate this major public health problem and create a more equitable and effective health care system. This article describes the method of PAR, supports the appropriateness of PAR to learn about and reduce health disparities, and then presents some specific examples of research projects that have employed or are planning to employ PAR. These examples are from

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the work of several authors of this article, who are members of an interdisciplinary working group that serves as a forum for discussion of issues related to qualitative research methods and facilitates the development of qualitative studies. All of the authors of this article are part of a task force of this working group that is focusing specifically on community outreach with the goal of reducing health disparities within specific communities.

Unequal access to affordable and effective health care is a critical and complex problem in the United States.¹ Although amazing breakthroughs have been achieved in caring for people with countless diseases and, in many cases, curing people with specific diseases, such as various bacterial infections and some types of cancers that are detected at an early stage, not all Americans benefit from such breakthroughs. Rather, those in higher socioeconomic strata, those who are not people of color, and those in urban areas have much greater access to health care than others. Health disparities are recognized as comprising a major public health issue and researchers are increasingly aware of the need to better understand the causes and consequences of such disparities in order to ultimately eradicate them.² A type of qualitative research method, referred to as participatory action research (PAR),^{3,4} is particularly suited for systematically learning about the conditions under which people experience health disparities, what it is like from the perspective of those experiencing such disparities and, even more importantly, how to ameliorate this major public health problem and create a more equitable and effective health care system.

This article presents an overview of the method of PAR, asserts why this method is appropriate to learn about and decrease health disparities, and provides some specific examples of research projects that have employed or are planning to employ PAR. These

examples are from the work of several members of an interdisciplinary working group that serves as a forum for discussion of issues related to qualitative research methods and facilitates the development of qualitative studies. These members are all part of a task force of this working group that is focusing specifically on community outreach with the goal of reducing health disparities within specific communities.

Participatory action research: the method

Participatory action research, founded in the work of Kurt Lewin,⁵ who is believed to have coined the term “action research,” is a form of qualitative research that seeks to understand human experiences, but goes beyond understanding to taking constructive action to ameliorate difficult, often oppressive, situations. PAR is frequently used interchangeably with other terms, such as action research, cooperative inquiry, community-based research, and others. Community-based participatory research is another commonly used term.⁶ Speziale and Carpenter⁷ aptly described the intent of all of these research approaches as seeking to empower others, particularly others who are marginalized, with the eventual goal of emancipating them from oppressive situations. Being denied equal access to adequate health care is a prime example of an oppressive situation.

A vital feature of PAR is that the researchers work collaboratively with the “researched” in an effort to achieve social justice in the form of improved conditions. By collaborating as partners with the “researched,” the researchers are pro-actively including those directly affected by the research. Rather than conducting a study “on” a group of people, these researchers are truly conducting a study “with” a group of people, integrating their perspectives and their input into all stages of the research process. PAR research focuses on a research question that is related to a social or community issue that involves oppression of a group of people; that is, a power differential that results in social injustice for several or a group of people. Representatives from that group of people are included, from the beginning, in the actual formulation of the research question. A typical approach to conducting the research is a focus group where community participants engage in open discussion with researchers about their experiences in relation to the particular issue being studied.⁸ The analysis of data is conducted collaboratively with the community participants in order to reflect, as closely as possible, the actual experiences of the people. The data are used as evidence for the need for change and for specific directions for change. An important step in this research process is advocating for social change. Such social change is advocated for collaboratively by all groups involved in the research. PAR is an iterative process where, as with all qualitative research, data are collected and analyzed, leading

to more-focused data collection and further-focused data analysis.

Seymour-Rolls and Hughes⁴ described 4 “moments” that comprise PAR. These moments are: reflecting, planning, acting, and observing. Reflecting refers to focusing on the shared concerns of the members of the research team in an effort to clearly define the research problem being studied. In PAR, this means that the entire research team, including the research participants/community members will meet together and discuss their views and concerns. For example, a member of a lower socioeconomic community may not share the same priorities in regard to health promotion as the traditional “researchers” and this would need to be discussed, based on mutual reflection and sharing of perceptions on the issues of concern. Planning refers to the process of developing the strategies involved in conducting the research project. In PAR research, all the members of the team, including the community members, will develop strategies for gaining entrée into the community within a context of trust. There is a better chance of developing trust by having community members as part of the research team. Acting refers to the actual implementation of the strategies developed in the planning moment. As with reflecting and planning, community members are involved in the actual implementation of the research, leading to enhanced communication among all the research participants. Observing refers to the analysis of data and is very much intertwined with the acting moment. By including community members in the analysis of data, it is more likely that the data analysis will reflect the perspectives of the research participants. All 4 of these moments actually occur iteratively, as there are several cycles involved and each of these moments occurs in each cycle.

Through the process of participation and collaboration among the research team, which includes those in the community who are traditionally viewed as the research “subjects,” greater insight and understanding of the phenomenon of interest is achieved. Those who are traditionally the research subjects are actually the “insiders,” presenting the “emic” view, and those who are traditionally the researchers are actually the “outsiders,” presenting the “etic” view.⁷ Both of these views are necessary and important to truly achieve collaboration and to help each of these groups understand the perspective of the other so that, ultimately, they can work together to achieve constructive change based on a complex understanding of the “emic” and “etic” views. Thus, there are multiple stakeholders in PAR, encompassing the “emic” and “etic” views.

Participatory action research: application to the study of health disparities

Health disparities comprise an overt example of social injustice in a societal context where health care is

considered a right for all persons. Although others may argue that health care is a privilege rather than a right, those who espouse a stance of social justice and equality tend to support the concept of health care as a right. If health care is a right, but only some people have access to high quality health care, a situation of inequality and injustice exists. Without any systematic research on this issue, policy makers are able to “turn the other cheek” and ignore the human aspects of this situation. On the other hand, conducting research that documents the problem without addressing solutions, while a beginning, is not enough. PAR is a research approach that includes both documenting specific problems and actively working toward solving the problems. This method is receiving greater attention for its potential to effectively address problems related to health disparities.⁶ The Institute of Medicine identified this method as important to be included in health professional schools’ curricula.⁹ PAR has been used to learn about health concerns in American Indian communities,¹⁰ in South Asian immigrant women,¹¹ and in Aboriginal grandmothers,¹² to name a few studies that have addressed health disparities.

The key principles of PAR, described by Seymour-Rolls and Hughes⁴ make this method especially appropriate for studying health disparities in order to eventually reduce them. These principles are: participation/collaboration, empowerment, knowledge, and social change. Participation and collaboration from all of the stakeholders encourages the active involvement from community members who are directly affected by the health disparities and whose input, therefore, is critical for eventually arriving at a constructive solution. Through this active partnership with the researchers, the community members will feel a sense of empowerment, which should further their active involvement in the ongoing work. In addition, through empowerment, the community members will truly feel that they are part of the research team and will have a greater trust in the researchers. The researchers will gain important knowledge and insight into the conditions under which the health disparities exist and will develop an appreciation for the complexities involved in developing and implementing effective strategies for reducing these disparities. The goal of PAR, which is social change, will have a higher likelihood of being achieved successfully through this ongoing and dynamic partnership between the researchers and community members.

Examples of participatory action research studies

This section provides several examples of participatory action research studies that are currently being conducted or are in the planning phase that address problems related to health disparities. Each of these examples highlights the strong community/collaborative focus, the local emphasis, and the action-oriented goals.

That is, each study consists of researchers working collaboratively with community members, these community members are people within a local context, and this research partnership has the ultimate goal of making constructive social change that will contribute to reducing health disparities. Although it is hoped that results from such studies will have applicability to other groups more globally (eg, have generalizability across populations), the more important goal in these studies is to create positive social change within the particular local community, which is a key feature of PAR. Most of the studies presented in this article are still in progress, making it difficult, at this time, to present outcomes that indicate evidence of actually reducing or eliminating health disparities. However, one of the studies (“Families in Motion”, described below) did find that the African American women in this study successfully implemented a walking program to contribute to improved health, evidence of the success of the PAR approach to reducing health disparities. It is hoped and believed that as all of these studies progress, further evidence will be available of the effectiveness of PAR to reduce health disparities.

Participatory Action Research with Somali Refugees

The eighth author of this article (Upvall) is currently developing a PAR study with Somali refugees. For the past 10 years, Somali Bantus escaping civil war lived in the Dadaab and Kakuma refugee camps in Kenya. These refugees are now being relocated throughout the United States and represent one of the largest groups for resettlement since the 1990’s.¹³ Pittsburgh, Pennsylvania will be home to 181 of these Somali refugees by the end of 2004.¹³ The majority of these Somalis are children who were born in the refugee camps, not knowing any permanent home nor having a formal education. Few of their parents speak English and there are even fewer Somalis living in the area to serve as translators. The first months of resettlement can be confusing as many Somalis have never used electric appliances, public transportation, or even shopped in grocery stores. Well-established organizations such as Catholic Charities have been instrumental in bringing the Somalis to Pittsburgh, but may feel overwhelmed by the numbers of refugees needing basic services. Community organizations, especially churches and the local mosque, have responded by developing networks of volunteers. Also, The Pittsburgh Refugee Center was recently created to specifically begin working with the Somalis.¹⁴ However, volunteer efforts can be sporadic at best. Organization is required to meet the pressing physical and psychological needs of this vulnerable group who have been exposed to war and deprivation at many levels. A Participatory Action Research project is currently being designed to provide a way for both the Somali refugees and volunteers helping in the resettlement.

ment process to identify their problems and potential solutions within the context of the Pittsburgh area. Separate focus groups are being planned for the refugees and volunteers. Each focus group will identify issues centered on the initial resettlement process. Future focus groups will be specifically designed to address problems identified by the initial groups. For example, a group of pregnant or newly delivered Somali women may discuss obstacles to receiving prenatal care. Concerns related to reversing female circumcision and identifying and treating posttraumatic stress disorder symptoms could be the focus of other groups. There is a wealth of practical information to be gained from the Somali refugees and those assisting them. Few studies are available that provide understanding or can be applied to the immediate needs of Somali refugees. This PAR study will provide the foundation for community programs and the development of handbooks necessary for guiding resettlement efforts. Encouraging new Somali refugees to share their frustrations as well as positive aspects of resettlement may ease the process for future refugees.

In this example of the Somali refugee study, there is a clear partnership between the Somali refugees, the volunteer networks who are assisting them, and the researchers. There is an overt goal of making constructive change that will facilitate the refugees' transition to a new country with a specific focus on health care issues in an effort to prevent the disparities in health care that likely occur with immigrant populations. The study is focused on a local community in which there are a significant number of Somali refugees.

Participatory Action Research with People of Color at the End of Life

The seventh author of this article (Stubbs) is currently working on a study focused on end-of-life issues for African Americans. The Take Charge of Your Life Partnership (TCP) is a network of consumers, professionals, community organizations, and corporations dedicated to educate, support and empower all people to deal with end-of-life issues. Originally named the End-of-Life Partnership of Western Pennsylvania, this action-oriented Partnership formed in 2000 in response to the national outreach associated with the Bill Moyers' PBS Special "On Our Own Terms." The Partnership is a 501(c)(3) nonprofit corporation with a traditional board structure.¹⁵ The Take Charge of Your Life Partnership was interested in investigating local concerns about death and dying. Its first project was to investigate the concerns expressed in data collected from 461 callers in the phone bank held by WQED (local PBS affiliate) during the original and then rebroadcast of the Moyers' special. These data highlighted the public's need for more information about disease-specific dying, including how people with alcoholism, mental illness, or Alzheimer's disease experi-

ence dying; caregiver stress; advance directives; and communication problems at end-of-life.¹⁶ In partnership with The National Issues forum, TCP sponsored over 25 community forums, soliciting concerns about death and dying from over 400 people. The Community Forums project was highlighted in a special issue of the *Journal of the American Medical Association*.¹⁷ In a second community-based research project, TCP members analyzed the feedback from participants in the forums. Of great concern was that the forum data revealed that few people of color were attending the forums to offer input about their concerns related to death and dying. These findings created the stimulus to actively seek out partners within communities of color in order to address the needs of those communities in regard to end-of-life issues. Ongoing research is being conducted to learn about issues of concern related to end-of-life in underserved and minority populations.

This study is an example of a strong partnership between researchers and community members as they, together, explored issues salient to those at the end of life. In the process of doing so, the lack of representation of people of color became apparent. This finding then led to a concerted and systematic effort to conduct further research in partnership with local community members representing people of color with the goal of addressing their specific needs and creating effective strategies to meet these needs in relation to end-of-life health care.

Participatory Action Research for Wellness in an African American Community

The fourth, fifth, and sixth authors of this article (Dodge, Hughes, Ondeck) are actively involved in a community outreach project at Magee-Women's Hospital, part of a designated Center of Excellence that focuses primarily on minority health. Families in Motion, a project that was developed by these researchers through their partnership with an African American community, is an intergenerational project to increase physical activity in predominately African American communities. It was first established in the fall of 2002 and was replicated in 2003 with funding from the Department of Health and Human Services. The project addressed prevention needs at the community level with an 8-week walking program. The program was developed with the community advisory board of the African-American Womancare Committee. The success of the first program in the Hill District of Pittsburgh, a predominantly African American community, and subsequent funding led to replication of the project in 2 additional communities in 2003. In 2004, two community agencies requested information to replicate the program with under-served minority and vulnerable populations. The Magee-Womens Hospital Community of Excellence works with the University of Pittsburgh Center for Minority Health at the Graduate School of

Public Health and a satellite office located on site at Magee-Womens Hospital on a joint community-walking project. Both centers promote the Families in Motion-focused community approach and the Walking DIVA's. The Walking DIVA's are a group of like-minded women who walk together for physical activity and social support. The name DIVA is not an acronym, but is a term used to represent "classy women," derived from the term related to women singing in operas. This project is intended to address the increased risk African American women have for diabetes/obesity. The Magee-Womens Hospital Center of Excellence is participating with the Urban League and the Center for Minority Health at the University of Pittsburgh to write the Black Papers, which documents this risk. Further research is being conducted to design, develop, implement and evaluate a train-the-trainer component to Families in Motion. The new project will target provider education/training to facilitate replication of Families in Motion in up to 16 additional at-risk communities. In addition, an evaluation plan will be developed to access the health outcomes for the participants.

This study is an example of a strong community partnership that was formed to study the risks for diabetes and obesity within a local neighborhood of African American women. Through this partnership, data were collected and analyzed, resulting in innovative and constructive strategies to decrease the risk factors, and this project is ongoing, based on ongoing data collection and analysis, reflecting the iterative process involved.

Participatory Action Research with African American and Caucasian Pregnant Adolescent Smokers

The third author of this article (Braxter) is currently developing a PAR proposal to learn about, and eventually decrease, the rate of smoking during adolescent pregnancy. Prenatal smoking remains a major public health problem that is associated with a number of adverse outcomes.¹⁸⁻²¹ Adolescents have the highest rate of prenatal smoking compared to other age groups of women. Caucasian pregnant adolescents have a higher rate of prenatal smoking than their African American counterparts,²² but African American pregnant adolescent smokers overwhelmingly smoke mentholated cigarettes, which is not so for their white counterparts, and mentholated cigarettes have been linked to habituation or failure to quit.^{23,24} In order to design effective smoking-cessation programs for pregnant adolescent smokers, researchers must be aware of racial/ethnic differences in smoking behaviors and patterns related to nicotine dependence. This study is designed to employ focus groups to collect data on African American and Caucasian pregnant adolescent smokers' understanding of nicotine dependence and their physiological and psychological symptoms of

dependence. The study proposes to assess cultural and socioeconomic contextual factors that affect smoking behaviors in the 2 groups. By focusing on the contextual factors, the problem of prenatal adolescent smoking behavior will be understood from a social perspective that is likely related to unequal access to resources and knowledge. The adolescents in the focus groups will be active collaborators and partners in this study.

This study is an example of a proposed community partnership to be formed in order to study a serious public health problem in 2 racial groups, African American and Caucasian pregnant adolescent smokers. The ultimate goal is to develop strategies to decrease the rate of smoking among adolescents during pregnancy. Through this partnership between researchers and adolescents, mothers and babies in this community will benefit as a result of the development of effective smoking cessation interventions.

Conclusions and summary

PAR is a form of qualitative research that focuses specifically on issues related to oppression and injustice. Health care disparities represent an area of great concern to PAR researchers. The key components of PAR include collaboration and partnership with those who are normally considered the subjects of a research study; empowerment of oppressed members of a community; development of knowledge from both an "emic" and an "etic" perspective; and a strong focus on social change via action strategies that evolve directly from the research data.

In this article, 4 examples of PAR research were presented. These are actual examples of studies currently in progress or proposed. Each of these examples emphasize the importance of developing partnerships within the local communities involved and has an ultimate goal of creating constructive social change that will lead to reduction in various aspects of health care disparities. PAR provides an approach to research that will not only lead to greater understanding of the conditions under which health disparities arise, but will also assist in developing strategies to reduce these disparities, leading to a more just and equitable health care system.

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