

Participatory Action Research in Advocacy and Social Justice in Women's Health

Introduction

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Public health research and practice today faces many new challenges. There have been major threats to human security; natural disasters from tsunamis, hurricanes and earthquakes; violent deaths from civil unrest and population displacement; terrorism; new and emerging pandemics ranging from HIV/AIDS to Avian influenza; and persistent and chronic disease from worsening poverty and social inequalities. These challenges create and sustain vulnerabilities that require new and innovative interventions to take account of the importance of the power differentials between the vulnerable and marginalized most affected by these threats on the one hand, and researchers, practitioners and policy makers whose role it is to explore and address these issues on the other. Recent events such as the hurricanes along the coast of the US brought into stark reality the non-randomness of the distribution of disadvantage and the persistent vulnerabilities in particular sectors of communities. They also highlighted the lack of evidence on the most effective ways of working with marginalized communities to optimize health interventions.

Traditional research paradigms that employ the structured research tools offered in epidemiology, controlled trials and other intervention research are increasingly ineffective in responding to dynamic social, cultural and environmental contexts. In part, these approaches reflect investigator driven research priorities. In addition the study designs require the "control" of factors considered external to the variables of interest that may otherwise compromise the interpretation of the data. Without discounting the merits of this type of evidence, there are clear difficulties in integrating interventions that are designed on the basis of evidence obtained under

structured and controlled conditions, into the realities of daily existence of communities that face persistent vulnerabilities.

Advocacy, in these instances, plays a critical role in ensuring social justice in situations of vulnerability. The advocate represents those unable to represent themselves in addressing power differentials and striving for equity. However a major part of public health discourse discounts the importance of advocacy because of the strong moral underpinnings, subjective nature of the process and perceived weakness of its evidence base. In addition, where advocacy has led the development of interventions, the evidence base for monitoring and evaluation is at best, very thin. Research approaches are therefore needed that are flexible and responsive to changing demographics and increasing vulnerabilities, and that allow for advocacy where appropriate but without compromising the robustness of the methods or the reliability and validity of the findings. Such approaches are possible through combining phenomenological approaches from anthropology with the underlying principles and positivist approaches embodied in more conventional public health research.

In this special issue we bring together a unique selection of papers that demonstrate the importance of and outcomes from the role of researcher as advocate and the use of community based participatory action research. The health issues are varied as are the range of backgrounds and communities with whom research was conducted. The common theme across the community groups was marginalization; for most, opportunities had not presented for the collection of data to demonstrate their level of need or appropriate and effective ways in which the needs could be addressed. The studies were based in Australia, New Zealand and the US and the communities are those of resettling refugee women, rural women and Indigenous women in Australia and New Zealand and of Hispanic migrant women and victims of domestic violence in the US.

Community Based Participatory Research (CBPR): Moving The Paradigm Into The Future

Collaboration between academics and community partners is a complex issue. McAllister et al. (2003), describe the growing acceptance of community-based participatory research among public health researchers and begin to “pull apart” what the term *collaboration* means. These authors conceptualize collaboration as a relationship that is facilitated by hiring community members at the onset of a research project and by promoting an atmosphere of teamwork throughout project conceptualization, data gathering, analysis, and dissemination of results back to the community. Eliciting community members’ opinions and perspectives throughout the research process allows researchers to refine their questions and approaches as they move through the research project. McAllister et al. (2003, p. 1673) conclude that to be effective, community-based research should be based on

1. Collaboration between researchers and community-based partners in determining research focus and design,
2. Community-focused recruitment of research participants,
3. Full use of the expertise of community-based research staff,
4. Shared oversight of the research process, and
5. Sharing of preliminary findings with community partners and incorporation of their interpretations in further analyses.

The papers in this volume describe different levels of community participation in the research process; each paper describes an implementation of the CBPR model that is uniquely tailored to the research questions and needs of the particular study community. The Indigenous women in Australia initiated the project on cancer and invited the researchers to support and work with them on what was for them, a health priority (Manderson and Hoban). The refugee women in

New Zealand and Australia negotiated changes in a researcher driven project and thereafter, took an active role in the way the project evolved (Guerin, Allotey et al). The rural Australian women had full control of their program of support and the role of the researcher was largely as an observer to their advocacy development (Warren, Markovic et al). An anthropologist-advocate was invited by the director of a domestic violence program to engage in long-term ethnography and to critically describe the social processes at work among victims of domestic violence, their children and the professional who try to ameliorate this difficult situation (Schow). Hispanic women and researchers worked together in the rural Western U.S. for five years studying the problem of type 2 diabetes, educating the community as a whole about the health effects of this disease and advocating for access to appropriate health education and medical care for those who suffer from this disease (Cartwright et al). The common theme that runs through these articles is the expressed need of women in the communities to avoid the sanitization of the many variables present in their particular life situations that are integral to their experiences of ill-health. The roles of the researchers as advocates and the effects of this on the research findings are also explored in the following articles.

Taken as a whole, these papers demonstrate that CBPR is a flexible paradigm within which scientifically rigorous research can be carried out while attending to the felt needs of the community members. Anthropologist Merrill Singer conceptualizes advocacy on a continuum that moves from purely knowledge-oriented advocacy that includes teaching and writing in a manner that promotes human understanding and demands an acknowledgement of the suffering of oppressed group, to a more action-oriented advocacy where the anthropologist promotes the specific interest of a subordinate group (Singer 1990 p.549). Explicit and critical witnessing and writing along with finely tuned, community-based, participatory research work provides the conceptual and ideological groundwork of the approaches used in this special issue of *Women and Health*

Advocacy and Social Science: Evolving Considerations

CBPR as a research strategy is not a static approach; as community members gain knowledge and control over research methods and the use of data, existing hierarchies of power within health research will change. As social scientists work alongside community members, not only are research results shared with the community, but also the community members themselves can engage in the process of education and professional development that will allow them to become full members of the community-based research teams. The papers in this volume describe communities at different levels of knowledge about and use of CBPR. Control over the implementation of the projects and dissemination of results varies between projects and over time within the same research projects. For instance, in the Hispanic communities focusing on the study of type 2 diabetes, community members were first involved as bilingual interviewers, then became permanent members of the on-going research projects housed at a local university (Cartwright et al) and currently, several of these individuals are enrolled as undergraduate and graduate students who are actively creating their own expertise in health research. Understanding how power evolves over time in CBPR research is a topic for future research consideration.

Another topic for future research is a more refined understanding of the effects of the proliferation of new communicative technologies on CBPR. Cell phones, video cameras, and personal computers are changing patterns of access to information and to real-time knowledge of events on a worldwide basis. Individuals living in remote regions are now often capable of communicating directly with the larger world without the need for academic or other intermediaries. What will be the ramifications of these changes for social scientists whose research focuses on community health and disaster planning or on the more urgent needs of individuals living in vulnerable situations such as refugee camps or other kinds of temporary accommodations? The processes of advocacy and community-based research on public health issues will need to evolve along with these changing social realities. The papers in this volume

illustrate that sound scientific research can be carried out while advocating for social justice with respect to chronic and emergent health problems in a variety of cultural and regional settings.

References

McAllister, C. L. et al. (2003). Parents, Practitioners, and Researchers: Community-Based Participatory Research With Early Head Start. *American Journal of Public Health* 93(10). 1672-1679.

Singer, M. (1990). Another Perspective on Advocacy. *Current Anthropology* 31(5). 548-550.