

Book Review

Cancer on the Margins: Method and Meaning in Participatory Research

**Edited by Jennifer J. Nelson, Judy Gould, and Sue Keller-Olaman, 2009
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Reviewed by Jill M. G. Bally

Jennifer J. Nelson, Judy Gould, and Sue Keller-Olaman have effectively collaborated to compile a collection of essays based on findings from numerous research projects undertaken by the Ontario Breast Cancer Community Research Initiative. The content of *Cancer on the Margins: Method and Meaning in Participatory Research* is substantive, and it is presented as theoretical and experiential tools for understanding and becoming familiar with participatory research. The editors have captured and intricately combined the experiences of women with breast cancer from marginalized groups such as Aboriginal, lesbian, francophone, rural, and low-income women, with the complexities, processes, and challenges that are inherent in community-based and participatory research methods.

The table of contents familiarizes the reader with the inner workings of the book, providing an outline that mirrors the qualitative research process, particularly as it relates to participatory research methods. Collectively, the chapters address important epistemological, methodological, ethical, and theoretical issues inherent in designing a study. These include data analysis, the crisis of representation, and the dilemmas related to reflection and reflexivity that exist in participatory research. In addition, the book provides an overview of the possibilities of “moving knowledge,” with an emphasis on change and social justice.

Specifically, each of the 12 chapters begins with an introductory map of its content and contains a table highlighting and synthesizing the essential elements of the study or studies embedded in that chapter, such as why the research was conducted, the methods used, and the key findings. On getting started in research with marginalized populations, for example, chapter 1 utilizes the Francophone Women With Breast Cancer Project and the Cottage Dreams Initiative to demonstrate the research process, from drafting research questions, to recruiting partici-

pants, to gathering data. The contributors highlight important methodological questions and challenges, such as the role of the researcher, the involvement of the community, and time considerations.

The analysis of the experiences of vulnerable and marginalized women on their cancer journeys, and the position of participatory researchers on collaboratively uncovering these experiences, is enlightening and informative. It provides health professionals, students, and both qualitative researchers generally and participatory researchers specifically with valuable insights into the lives of such populations and offers insight into the processes and conundrums related to participatory research. In keeping with participatory research, the emphasis is placed on the power inequities between researchers and participants and between participants and the communities and health-care structures within which they live and experience health and illness. The reader comes away with an awareness of not only the particular challenges and issues faced by marginalized women on their breast cancer journey but also those experiences that are associated with participatory research. As with participatory research itself, *Cancer on the Margins* is filled with the voices of participants in the form of riveting passages taken from their experiences, and they are seamlessly woven into the contributors' descriptions of the research process. The result is a rich description of the intersection of both journeys — that of women making their way on their unique journey with breast cancer and that of the researcher traversing the ground of community-based and participatory research projects with vulnerable populations. The highlights of this intersection affect the participatory research process. The authors identify these as key considerations and include the development of effective partnerships and capacity-building in the community, shared power, learning and knowledge-generation in working towards social equity, reflexivity, and transformative outcomes.

Most importantly, the editors point out that this book does not purport to resolve all issues and answer all questions. In fact, *Cancer on the Margins* is not a prescription to follow, as one size does not fit all in such emergent and responsive research projects. The value of the book is its insider's perspective and an awareness of the loopholes, considerations, approaches, and challenges that one may encounter in conducting participatory research, as well as the rewards of such work. The contributors present their research projects and, through reflection, pose critical questions about the challenges that emerge within each chapter. Again, the book's usefulness and resonance spring partly from the fact that the contributors are true to participatory research and, indeed, practise what they preach. They reveal their thoughts, reflections, and practices by critically examining each research project presented in order to deliver the

experiential tools necessary to build research using similar methods. This process provides ample guidance for the reader to conduct community-based and participatory research and offers adequate information for reflection prior to, during, and after such a project is undertaken.

Overall, *Cancer on the Margins* is a useful and memorable book that easily catches and holds the attention of the reader. It is both provocative and informative. By providing in-depth information about the ins and outs of conducting participatory research with a variety of vulnerable populations, it greatly enhances our understanding of qualitative research methods and the role of the researchers and the participants in sharing and creating knowledge. The editors have captured heartfelt experiences of both participants and researchers in a useful tool for conducting participatory research. As social justice becomes an ever more essential outcome of research in health and illness, this book is an exemplar for research that effects social change and levels the ground between the researchers and the researched. *Cancer on the Margins: Method and Meaning in Participatory Research* is highly recommended for those wishing to pursue research through community-based and participatory methods, for professionals who work with vulnerable and marginalized populations, for policy-makers, and for the general public.

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