

Participatory Qualitative Research Methodologies in Health

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What is Participatory Research? Why do it?

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Background

In the past few decades, we have seen a surge of work within the paradigm of participatory research (PR). The results have not only raised challenges to the practices of positivist science but have also led to many questions about the construction and use of knowledge and the importance of power relations that permeate the research process. More importantly, this work has brought to light new ideas about the roles of researchers in engaging with communities and local people and the capacity of the two partners to make society more just and equitable.

Aim

We will explore the notion that PR provides opportunities for marginalized individuals to engage in research and find solutions that benefit not only themselves but also others in their own communities (Higginbottom, Story & Rivers, 2014). Commitment to this research genre is most often motivated by concerns regarding equity.

Objectives

To contextualize the concept of PR by including debates on the nature of PR and its usefulness in qualitative research.

To explicate the various models of PR, delineating the boundaries and parameters of the genre.

We will include theoretical discussions, practical tips and case examples drawn from empirical research findings and practices. After reading this chapter, readers will be able to not only understand the concept of PR, its nature and its usefulness, but also identify various diverse models of PR.

Introduction

The fundamental premise of this text is that PR provides opportunities for individuals, groups and communities to actively participate and engage in the research process. The active collaboration of participants from the design stage through to dissemination and knowledge transfer will help them to find meaningful solutions that benefit not only them but also others within their social groups or communities (Bartlett, Iwasaki, Gottlieb, Hall & Mannell, 2007; Cargo & Mercer, 2008; Chinn, 2007; Green et al., 1995). Participatory research is the antithesis of ‘elitist research’, which has as its central tenet that all the power, knowledge and authority is vested within the professional researcher (Cargo & Mercer, 2008; Tilakaratna, 1990). Elitist research gives primacy to the perspectives of those who hold scientific and professional knowledge, thereby marginalizing and relegating the perspectives of participants who then may be regarded as passive subjects in the research process. In PR, the emphasis is instead on bottom-up approaches (Cornwall & Jewkes, 1995; Green et al., 1995; Higginbottom et al., 2014; Reason & Bradbury, 2006), based on the notion that locally conceptualized research may be more efficient and economical in responding more meaningfully to local priorities. Central to the concept of PR is an acknowledgement of the trilogy of power, people and praxis.

Qualitative research is characterized by the acceptance of multiple social realities (Creswell & Clark, 2011; Denzin & Lincoln, 2011; Liamputtong, 2013). PR regards participants as being knowledgeable about their own social realities and best able to re-articulate this knowledge as research evidence (Higginbottom et al., 2006). In sociological terms, pre-eminence is afforded to the agencies of the participants and communities involved (Cornwall & Jewkes, 1995; Green et al., 1995). Cargo and Mercer (2008) provide a useful definition of PR as a ‘systematic inquiry, with the collaboration of those affected by the issue being studied, for the purposes of education and of taking action or effecting change’ (p. 328). Participatory research emphasizes the notion of ‘voice’ in the study participants, acknowledging that the personal biases and orientations of the researchers can affect their work: we all have a tendency to filter and reinterpret data in the light of our own worldviews. This filtering most often materializes in the researchers selection of verbatim comments to support conclusions and recommendations. The International Collaboration for Participatory Health Research (ICPHR) (2013) provides useful position statements on the concept of participatory health research and comprehensively defines the methodology.

Conceptualizing PR and its usefulness in qualitative research

In this text, we conceptualize the term *participatory research* as a collective umbrella term that embraces a number of methodological genres. Others have described this overarching term as a ‘school of approaches that share a philosophy of inclusivity’ (Cargo & Mercer, 2008: 326). Regardless of the terminology adopted, all of the discrete genres of PR involve co-construction of the research processes and products (Jagosh et al., 2012). Some of the various genres will be discussed in detail later in this chapter.

A brief historical review of the origins of PR reveals several distinct precursors and lines of evolution. Forms of PR have origins in Latin American political activism and in bottom-up approaches to challenging the oppression produced by poverty and illiteracy (Cargo & Mercer, 2008; Pant, 2009; Weller & Malheiros da Silva, 2011). These antecedents arise from the philosophies of Paulo Freire and his propositions with respect to education as a liberating force. This social movement (Cargo & Mercer, 2008; Pant, 2009; Weller & Malheiros da Silva, 2011) set the context for the evolution not only of specific forms of PR in Latin America but also of the acquisition of knowledge as a challenge to the oppression of the poor by elite and dominant groups within society. A fundamental premise of the ideologies of Freire is that marginalized groups within society are able to construct knowledge in valuable ways, and that such knowledge is meaningful and significant for these social groups and their communities.

These new approaches were not confined to the Brazilian context: examples also exist arising from other Latin American nation-states and from Africa and Asia (Oliver, 1992; Pant, 2009). Indeed, the work of researcher and sociologist Fals-Borda in Colombia during the 1970s significantly advanced and developed the genre of participatory action research (Fals-Borda, 1985; Fals-Borda & Rahman, 1991).

The origins of PR can also be traced back to the perspectives espoused by Lewin (1946). Lewin’s seminal text focused on action research and minority problems. He used the term ‘minority problems’ with specific reference to the experiences of minority ethno-cultural groups in the North American context (at the time of his writing, the populations of various ethno-cultural groups were proportionately smaller than they are now). His work was strongly focused on the notion of ‘intergroup relations’, which might be conceptualized today as the dynamics and politics of racial and ethnic relations.

In North America and Europe, the rise of PR also had some relationships to the social movements of the 1960s and 1970s, including the rise of feminist theory, anti-racism and anti-oppressive practice (Oliver, 1992; Pant, 2009). In later decades, the rise of PR was also related to increases in ‘queer research’ (Miller and Brewer, 2003) and lesbian, gay, bisexual and transgender (LGBT) research (Boehmer, 2002). More recently, PR methodologies have been used in studies with prison inmates

(Elwood Martin et al., 2009; McInerney et al., 2013; Sherwood & Kendall, 2013; Ward & Bailey, 2013).

In many respects, the development of PR in North America and Europe evolved in reaction to the predominant modes of inquiry: empiricism and positivism (Oliver, 1992; Pant, 2009). Thus, the goals of PR focus on the production of alternative forms of knowledge, and its ontological and epistemological foundations are divergent from those of elitist or conventional research (Cargo & Mercer, 2008).

Collectivism is a key feature of PR. Whereas conventional or elitist research may be driven by a sole investigator, PR is intrinsically a collective endeavour driven by the collaborative processes taking place between the researcher, the communities and the participants. Moreover, the process may be educative, empowering and multidirectional, and it may create new insights for the professional researcher and the communities involved in the research (Cargo & Mercer, 2008; Pant, 2009). Pant (2009: 100) describes three critical dimensions of PR:

- Development of critical consciousness for both the researcher and the participants.
- Improvement of the lives of those involved in the research process.
- Transformation of fundamental societal structures and relationships.

Contemporary PR methodologies have evolved as processes of co-construction involving community members, patients and their families, clients, specific cultural groups and researchers (Higginbottom et al., 2006; Jagosh et al., 2012; Weller & Malheiros da Silva, 2011). Some researchers have claimed that conventional or elitist research promotes iatrogenic effects (Jagosh et al., 2012), meaning that engagement in conventional or elitist research can have negative consequences for those participants who are not regarded as equal partners in the research process. This iatrogenesis may manifest in a number of ways, including a misrepresentation of ideas and perspectives, a lack of cultural congruence and cultural sensitivity in the research process, a misinterpretation of the findings and stereotyping of the participants. These consequences lead to feelings of exploitation among the very participants that the research is expected to benefit.

Since PR methodologies devolve the power usually vested in experts and share it with participants, such methodologies challenge the hegemony of academia and professional research practice; indeed, non-academic research partners are often regarded as being more knowledgeable and expert in some domains (Higginbottom & Serrant-Green, 2005; Liamputtong, 2010). The fundamental tenets and axioms associated with PR methodologies are thus appropriate and indeed desirable for conducting research with marginalized communities (Liamputtong, 2007, 2010, 2013). The generation of new knowledge via PR does not rest with professionals alone: knowledge production and ownership is shared with participants (Green et al., 1995; Pant, 2009). In fact, the production of just knowledge alone is not the goal; a key dimension of PR is the utilization and implementation of research products such that they have a meaningful and translational impact on the lives of

the engaged social group, community or individuals. Table 1.1 outlines the characteristics considered universal to PR.

TABLE 1.1 What are the universal characteristics of PR?

Research task	Ownership by participants and researchers
Goals of the research/topic setting	Defined by participants or community, but may be academically articulated by the researcher.
Setting of research questions	Co-constructed by the participants/community and researcher.
Operationalization of the research	A process of mutual cooperation between the participants/community and researcher.
Acquisition of funding	Usually, though not exclusively, the researcher.
Data collection processes	Co-constructed by the participants/community and researcher.
Data analysis	Co-constructed by the participants/community and researcher.
Interpretation of the findings	Co-constructed by the participants/community and researcher.
Knowledge transfer	Co-constructed by the participants/community and researcher.
Implementation of findings	Participants/community.
Authorship of research products	Both the participants/community and researcher.
Research collaborations	Long-term commitment between the participants/community and researcher.
Educative and critical consciousness dimensions	A mutually beneficial and reciprocal cyclical learning process.
Knowledge translation	Knowledge transfer and implementation in multiple spheres, including praxis and political spheres. Usually, but not exclusively, a challenge to inequity.

A major strength of PR is its potential for integrating academic and theoretical perspectives with lay and implicit knowledge to unveil new insights and understandings of the phenomena under investigation (Cargo & Mercer, 2008). PR enables the lived experience of participants to be integrated with theoretical and academic knowledge. The contextual and situational nature of this lived experience fundamentally configures the generation of new knowledge and insights.

Theoretical perspectives

Historically, PR was based on the cultivation of ‘conscientization’ (critical consciousness) among oppressed peoples, as theorized by Freire in his book *Pedagogy of the Oppressed* (1970). PR has its theoretical framework in ‘linking the process of knowing to learning and action’ (de Koning & Martin, 1996: 5). Freire argued that

individuals link knowing and learning through a continuing cycle of action and reflection. This linkage then leads to the acquisition of a 'critical awareness' about the world in which they live. In criticizing general practices in education, Freire contended that most educational activities do not challenge inequalities in the learners. Most such activities keep the learners passive and uncritical, and they fail to help people question the situations in which they are forced to live. The application of Freire's theory in the health area was discussed by de Koning and Martin (1996). These authors contended that a conventional didactic approach in health education about hygiene and nutrition failed to enable people to critically examine the reasons for them not having enough water and food or to identify ways in which 'political, social, and personal action' (de Koning & Martin, 1996: 6) could alter their situation. It is thus not too surprising that many such health education programmes do not reach their target groups or achieve their goals.

Freire strongly encouraged individuals to realize that they are fundamentally responsible for making and transforming their own situations and realities. He also encouraged oppressed people to carry out research on how these realities and their effects have worked or could work differently in diverse social and political contexts. Primarily, Freire believed that these activities would assist oppressed people in having more control of their lives, and they could use this control to change the economic, material and ideological conditions of their realities. Freire's literacy programmes were constructed so that oppressed people's conscientization could be cultivated. He encouraged oppressed people to 'engage in "praxis" or "critical reflection"', which are inextricably connected to political movements in the real world (Kamberelis & Dimitriadis, 2008: 379). Through conscientization and praxis, Freire suggested people would be able to improve the conditions of their situations. He coined this as 'human agency'. Although its power may be limited, he believed human agency would be enough to enable people to change themselves and their situations for the better. To possess such agency, Freire argued, people needed to 'emerge from their unconscious engagements with the world, reflect on them, and work to change them' (Kamberelis & Dimitriadis, 2008: 379). Within Freirean pedagogies, the process of emancipation can only occur through the collective effort of oppressed people and this effort requires the power of dialogue. Dialogue, for Freire, referred not only to talk and discussion but also to collective action and reflection – precisely what PR is about.

We have also witnessed the emergence of the feminist movement in the debate regarding PR and in the development of PR (Maguire, 1996, 2004, 2006; McIntyre, 2008; Reid, 2004; Reid & Frisby, 2008). Feminism has had a great influence on reworking 'the conditions of knowledge production' and making it visible in PR research (Maguire, 2006: 67). Feminist researchers and activists around the globe have questioned the terminology of the 'oppressed', the 'marginalized' and the 'poor' used in PR. They argued that although the methodology aims to empower the oppressed, the marginalized, or the poor to take

control over their lives, it is questionable who these people are. The danger in the use of categories such as these is that they imply homogeneity among oppressed, marginalized and poor people (de Koning & Martin, 1996). In relation to PR, feminist critiques contain three points of concern. First, who is given a voice in a PR project? That is, who are included as participants, and whose ideas are represented in the findings? In the past, most PR projects represented mainly the voices of men, and women were largely excluded from the research (Maguire, 1996, 2001). Second, the use of categories such as the oppressed, the marginalized, or the poor, as used by Paulo Freire, raises questions about the development of theory in practice. As a male, Freire in his early writing failed to address differences between and among groups of oppressed people. In his later writing, however, he acknowledged the critiques of his work by feminist writers (for more detail, see McLaren & Leonard, 1993). Freire had used examples such as bosses oppressing workers and men oppressing other men. However, he had failed to look at situations where men who were oppressed in the workplace came home and oppressed their wives or daughters. Third, the meaning of being a woman differs depending on place, situation and time. Ethnicity, social class and age also influence the experience of being a woman. The use of *women* as a unified group is therefore problematic, and feminist researchers (particularly in underdeveloped countries) have challenged this categorization as well (Maguire, 2006). The historical antecedents of contemporary PR clearly link the evolution of the methodology to social justice issues.

The development of feminist theory has resulted in several PR projects addressing the issue of differences between men and women in the empowering and knowledge production processes. In her writing about PR from a feminist perspective, Maguire (1996) states the following:

Feminisms are about attempting to bring together, out of the margins, many voices and visions of a more just, loving, non-violent world. In that sense, feminisms and PR share emancipatory, transformative intentions. Yet in practice and theory, PR has often ignored the gender factor in oppression. (p. 28)

Maguire (2004, 2006) argues that feminist perspectives have shifted PR from being 'man centred' (as it was in the past) to 'human centred,' thus including women on the agenda of the research. We extend Maguire's inclusion of women to other groups. We argue that man-centred PR can be replaced by PR with other marginalized groups, including older people, children, people living with disabilities and ethnic minorities (see Chapters 6, 7, 8 and 9).

Following the framework of action research, PR is also situated within the *extended epistemology* theorized by Heron and Reason (1997, 2008), which includes experiential, presentational, propositional and practical knowing (Liamputtong, 2014). Heron and Reason (1997) refer to this extended epistemology as 'critical

subjectivity’ (p. 281). In PR, as in their everyday lives, people undeniably use these four forms of knowing and implicitly engage them in different ways. *Experiential knowing* is the foundational form of knowing. Individuals cultivate their knowing through their direct experiences – such as through their participation in a PR project. Individuals may voice their experiential knowing through expressive imageries such as stories, arts and performances. Heron and Reason term this as *presentational knowing*. Individuals make sense of their experiential knowing through propositions that are meaningful to them; this was coined as *propositional knowing*. According to Heron and Reason (1997: 281), propositional knowing refers to ‘knowing in conceptual terms that something is the case; knowledge by description of some energy, entity, person, place, process, or thing’. Individuals then cultivate *practical knowing* (competence or skill) and use it for actions in their lives so that they can change their situations to the better. These four forms of knowing are the essential bases of PR (Liamputtong, 2014). As other chapters in this volume will show, people are able to change their lived realities if they actively participate in a research project. Through active participation, they can cultivate the four forms of knowing and can ultimately be empowered to alter their marginalized lived realities (Baldwin, 2012; Heron & Reason, 2008).

Propositional knowledge, or formal theory, in western epidemiology is most often heavily dominated by positivist rationality (Baldwin, 2012). Individuals are treated as ‘objects of research’ and research is not ‘grounded in subjective, experiential, and practical knowledge’ (Baldwin, 2012: 469). This approach has alienated many people. In contrast, PR offers a model ensuring that the propositional knowledge is situated within the experiential knowledge of those who are part of the PR project and who are accepted as co-researchers. This propositional knowledge is co-constructed through the ‘democratic decision-making processes’ practised in PR (Baldwin, 2012: 469).

Models of PR

The universal principles of PR are broadly agreed upon (Cameron et al., 2010; Cornwall & Jewkes, 1995; Decker, Hemmerling & Lankoande, 2010), but the field is widely heterogeneous in terms of design and implementation. We will explore a number of specific genres or approaches in greater depth, but it should be noted that the genre boundaries are not always clearly defined and may be somewhat amorphous. Furthermore, the extent of community participation and the researcher–community relationship may vary to some extent between genres. Biggs (1989) describes four modes of participation that are points within a continuum of community participation:

- Researchers contract out services (contractual).
- Researchers consult with community engagement or advisory groups to inform the study design produced by researchers (consultative).

- Researchers manage the collective participatory work on a project (collaborative).
- Researchers and participants develop mutually beneficial relationships through which the community learns to function independently (collegial).

Even though researchers may fully intend to maintain a collaborative or collegial endeavour, some form of consultative participation may become necessary in many instances (Green et al., 1995). Figure 1.1 illustrates these four modes of community participation.

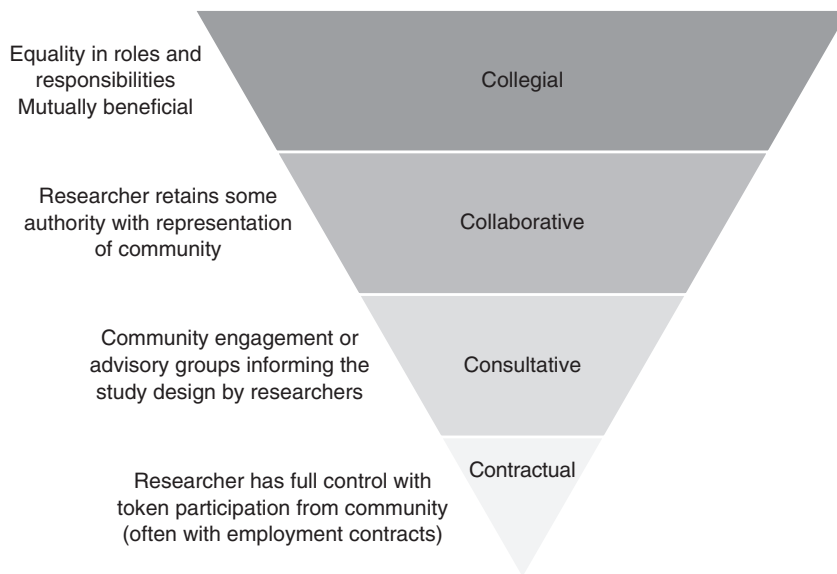


FIGURE 1.1 Modes of community participation

Community-based participatory research

Community-based participatory research (CBPR) signifies collaborative research with communities (Israel et al., 2008, 2010; Liamputtong, 2010). Minkler and Wallerstein (2008) provide a comprehensive text on CBPR that explores the methodology in detail from ‘process to outcomes’. CBPR often focuses on health (Dick, 2009; Israel et al., 2010; Minkler & Wallerstein, 2008; Parker, Chung, Israel, Reyes & Wilkins, 2010). Many exemplars exist within the literature and some have been reviewed by Viswanathan et al. (2004). Hebert, Brandt, Armstead, Adams and Steck (2009) provide a useful definition of CBPR as ‘a collaborative approach to research that equitably involves all partners in the research process and recognizes the unique strength each brings’ (p. 1213). Case 1.1 provides an example of CBPR. This approach is explored in more detail in Chapter 3.

Case 1.1 The Horn of Africa Blind Society

Using a CBPR approach was ideal to explore the health and social care needs of Somali refugees with visual impairment (VIP) in the United Kingdom (Higginbottom, Storey & Rivers, 2014). A focused ethnography was conducted with focus group interviews with key stakeholders – Somali people with VIP and their carers – and with the active participation of the researchers in the HABS community. Essential to the study was the ongoing involvement of the Horn of Africa Blind Society (HABS) – a voluntary group and a UK registered charity – in all study processes, including establishing the research questions and design, hiring of project staff (community research assistants) and analyzing and disseminating the findings. This close collaboration ensured that the findings were grounded in the realities of day-to-day life for Somali people with VIP. Our methodological approach was well suited to this participatory research as it allowed us to incorporate various perspectives to increase the comprehensiveness of the findings.

Participatory action research

Participatory action research, as the name implies, involves goal-oriented action that follows as a result of the research products. This approach is widely and comprehensively described in the literature (Cargo & Mercer, 2008; Cornwall & Jewkes, 1995; Dick, 2009). Diverse methods may be employed, but these various methods are all largely informed by ideological principles associated with the work of Paolo Freire (1970). Essentially, Freire maintained that the acknowledgement, recognition and indeed reduction of power differentials are fundamental to the eradication of inequalities. He also believed that these principles may be employed in a number of different spheres of activity, including education and health. Critical conscientization is a key feature, along with educative processes for all involved.

Cooperative inquiry

Cooperative inquiry is a PR strategy with clearly specified steps that involve iterative reflective processes (Heron, 1996). The term ‘iterative reflective processes’ refers to the constant and consistent use of dialogue, communication and collaboration between the researcher and the lay participants to ensure the continued negotiation of a shared agenda and goals for the research being conducted. In many respects, cooperative inquiry fundamentally refers to the joint and shared

values and philosophical stance of all concerned. In common with all types of PR, participants are regarded as co-researchers and co-inquirers. The focus is on a co-construction of the research processes and research products. A good example is provided in a study conducted by Manley, Webster, Hale, Hayes and Minardi (2008) that investigated the roles of nurse consultants who worked with older people in England. Instead of the research product being controlled by the investigator, each participant nurse consultant produced reflective narratives of their engagement with older people, and these narratives formed the core data for the study. Other exemplars of a cooperative inquiry approach include the studies of Tee et al. (2007) and of Hummelvoll and Severinsson (2005) within mental health care settings. Box 1.1 lists the five phases that constitute the cycle of cooperative inquiry (Heron, 1996).

Box 1.1 Five phases within the cycle of cooperative inquiry (adapted from Heron, 1996)

1. Bring together the participants
 2. Define the focus of the inquiry and agree actions
 3. Apply agreed actions and observe and record outcomes
 4. The group experiences the consequences
 5. The group learns from the experience and disseminates their findings
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Appreciative inquiry

Appreciative inquiry utilizes a cyclical iterative approach with four steps (Lazic, Radenovic, Arnfield & Janic, 2011). These steps are shown below in Box 1.2.

Box 1.2 Four steps in the appreciative inquiry cycle (Lazic et al., 2011)

1. Discover: the identification of organizational processes that work well
 2. Dream: the envisioning of processes that would work well in the future
 3. Design: the planning and prioritizing of processes that would work well
 4. Destiny: the implementation of the proposed design
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Decolonizing methodologies

The extreme oppression and subjugation experienced by Aboriginal and Indigenous people at the hands of colonial powers as well as the European

domination of developing nation-states around the world have been widely acknowledged. In response to the ongoing legacy of colonization, key theorists who have Aboriginal ethnic identities have challenged the dominant hegemonies and postulated new approaches to conducting research with Aboriginal peoples. Linda Tuhiwai Smith conceptualized a decolonizing methodology from the Maori perspective in her seminal text (Denzin, Lincoln & Smith, 2008; Smith, 1999). Theorists in other western contexts, such as in Canada (Bartlett et al., 2007; Bottorff, Carey, Sullivan, Varcoe & Williams, 2010) and in the Pacific Islands (Chinn, 2007), have further developed the methodology. Decolonizing methodologies reject western worldviews, lenses and ethno-cultural orientations, and instead often draw upon collective rather than highly individualistic approaches. The research processes are therefore collaborative and highly transformative (Chinn, 2007), each with a unique configuration to meet the needs of a specific community or ethno-cultural group (Liamputtong, 2010). In Canada, for example, specific guidelines now exist for conducting research with the First Nations, Inuit and Métis peoples of Canada (Canadian Institutes of Health Research, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada, 2010).

Democratic evaluation

The research literature is rife with discourse and polemics on the fundamental characteristics of research and evaluation. Research is often said to focus on the generation of new knowledge, whereas evaluation is thought to focus on the appraisal of existing phenomena or processes. However, the parameters of research and evaluation can overlap and merge into an 'ambiguous border' where evaluation is used to generate new knowledge. MacDonald and Kushner (2005) frame the approach of democratic evaluation within the pedagogical domain, and they restate MacDonald's earlier description:

The democratic evaluator recognizes value pluralism and seeks to represent a range of issues in his [her] issue formulation. The basic value is an informed citizenry, and the evaluator acts as broker in exchanges of information between groups who want knowledge of each other. (p. 110)

Ryan (2005) asserts that democratic evaluation is valuable in health studies and in addressing issues of equity and inclusion, and that it is fundamentally a case study approach – the case being the programme under evaluation. The fundamental goal is to democratize knowledge, ensuring that all the key stakeholders – commissioners, clients and service users – are mutually accountable while challenging the inherent power dimensions and facilitating a redistribution of this power.

Participatory evaluation

Ingram and colleagues (2012) provided an example of a participatory evaluation in a ten-year study among Mexican-American women that focused on a health promotion programme designed to promote physical exercise, fruit and vegetable consumption, and stress reduction. The authors defined participatory evaluation as ‘an essential tool for community-based organizations in tailoring programs to the needs of the populations they serve’ (Ingram et al., 2012: 130). Cousins and Whitmore (1998) provided further insights in their exposition of two branches of participatory evaluation. *Practical participatory evaluation* (P-PE), they asserted, has origins on the North American continent and is heavily oriented towards programme evaluation. Central to P-PE is the idea that key stakeholders are intimately involved in all dimensions to ensure relevance, applicability and utility. The second branch, *transformative participatory evaluation* (T-PE), is a highly politicized process having origins in Latin America, and its central goal is to ‘democratize social change’ (Cousins & Whitmore, 1998: 7).

Emancipatory research

Irwin (2006) asserts that the term ‘emancipatory research’ does not signify a unitary school of thought but rather refers to a collective genre of PR that shares similar ontological and epistemological origins. However, the fundamental precepts and axioms of emancipatory research are complex and involve core principles focusing on (a) the dynamics of power in relationships, (b) consciousness raising, and (c) oppression. This research approach has a strong relationship to the seminal work of Paolo Freire (1970, 1973) with respect to its challenges to dominant ideologies within society and the notion of critical conscientization. Other key dimensions are ‘intersubjectivity’ and ‘reflexivity’ (Rose & Glass, 2008), which are explored in depth in Chapter 4. A number of observers (Barnes, 2003; Irwin, 2006; Rose & Glass, 2008) have asserted that this approach is highly relevant for health-related research. Oliver (1992) offers the following description:

The development of such a paradigm stems from the gradual rejection of the positivist view of social research as the pursuit of absolute knowledge through the scientific method and the gradual disillusionment with the interpretive view of such research as the generation of socially useful knowledge within particular historical and social contexts. The emancipatory paradigm, as the name implies, is about the facilitating of a politics of the possible by confronting social oppression at whatever levels it occurs. (p. 110)

However, this definition might be considered somewhat unattainable and idealistic, considering the comments of Barnes (1996) that no researcher is completely

independent in the research process and that ‘academics and researchers can only be with the oppressors or with the oppressed’ (p. 110).

Using participatory research in health-related research

Many examples exist in the literature illustrating the use of PR methodologies in health-related topics (Bartlett et al., 2007; Jagosh et al., 2012; Rose & Glass, 2008; Young & Wharf Higgins, 2010). In common with the early conceptualizations of participatory methodological approaches, PR is often adopted where the focus is on health equity issues (Wallerstein & Duran, 2010) and on marginalized populations such as individuals who experience disabilities (Barnes, 1996; Ramcharan, 2005; see Chapter 8), Indigenous and Aboriginal peoples (Bottorff et al., 2010; Hebert et al., 2009; Smith, 1999; see Chapter 9), older people (see Chapter 6), and children (Irwin, 2006; see Chapter 7). In other words, perhaps, wherever individuals experience a lack of autonomy or a ‘voice’ in a given socio-political context, PR may not only enable these voices to be heard but may also provide a rearticulation of perspectives in the face of silence or opacity. Where societal institutions are distrusted by marginalized communities (Higginbottom et al., 2006; Higginbottom & Serrant-Green, 2005), PR may provide a pertinent mechanism for the engagement of individuals, groups and communities and afford them a greater degree of autonomy and control. Case 1.2 provides an example of the use of PR in health-related research.

Case 1.2 Participatory research with health professionals

One example of ours from outside the community setting, but concerned with health equity, was a PR project resembling Action Research, whereby managers at a tertiary care hospital approached us after having determined their need to identify an ethno-cultural nursing assessment tool for implementation in their care units. They had identified a clear need to enhance the quality of care for their increasingly diverse patient population. After the research team identified a potentially suitable tool (Higginbottom et al., 2011), we partnered with the senior management to conduct a pilot study aimed at investigating the suitability and acceptability of the identified cultural assessment tool – the Family Cultural Heritage Assessment Tool (FamCHAT) – in their setting (Higginbottom et al., 2012). The findings provided valuable information for the hospital management in their efforts to revise nursing assessment tools. Consideration is being given to integrating some of the constructs into their existing nursing assessment, with recognition that each unit might benefit from different approaches.

The domain of PR is replete with ambiguities in the terminologies employed to describe the various genres of PR. We have attempted to provide a broad overview of some of the commonly used approaches to PR, but some confusion may remain regarding the terminologies employed by the scientific research community. For neophyte researchers, this lack of clarity may militate against the use of PR. Throughout the text we will cite consistent 'academic models' for conducting PR, as many comprehensive and sophisticated descriptions exist in the literature.

Participatory research requires the establishment of credible and trusting relationships between researchers, individuals, groups and communities. The establishment of such partnerships is inherently time-consuming, therefore creating tensions between funding agencies (who may require rapid results and findings) and researchers who are philosophically oriented towards PR. The time needed to operationalize PR research studies is often substantial, because this input stage is an intrinsic characteristic of such research; however, the initial time investment may be offset by significant savings in time at the knowledge translation/exchange stage, since key partners and decision-makers have already been engaged in the research (Green et al., 1995).

Participatory research has become the subject of critical analyses and critiques by a number of observers (Kemmis & McTaggart, 2005). Debates have focused on at least four areas: the notion of empowerment and how this might be facilitated in PR; the claimed benefits of the collaborative nature of PR; the time-consuming nature of PR; and the actual reality of challenges to the power-structured relationships that may exist between researchers and community members (MacDonald, 2012). It was suggested that the positive dimensions of PR may have been exaggerated compared to what is achievable in reality.

A systematic review of all forms of PR is urgently needed (Cargo & Mercer, 2008) to demonstrate the efficacy, or lack thereof, of these methodological approaches, especially with regard to health-related topics and outcomes. Such a review would assist in strengthening the evidence base for the genre. We intend to provide – in a rigorous, scientific fashion – clear and robust evidence of the benefits of PR over more elitist forms of research.

Conclusion

This chapter has provided a theoretical exploration of the concept of participatory research as a methodological genre, including a review of its historical antecedents. PR is inherently linked not only to notions of justice and equity but also to a desire by both researchers and participants to equalize the power hierarchies and dynamics associated with the scientific research process. As will be shown in later chapters, this approach may be used with diverse population groups and in various situations.

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