

Participatory Action Research in Health Care

Tina Koch
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With contributions from Anne van Loon
and Susan Mann



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Dedication

To all the people we have researched with.

Acknowledgements

We wish to thank the many people who have helped in the construction of this book. We feel greatly indebted to those whose ideas and insights preceded ours and have consequently guided our work. This book is truly a tribute to the spirit of collaboration.

We have learned alongside many people. Chapter 9 was co-authored by our colleagues Drs Anne van Loon and Susan Mann, who were the project managers for the two inquiries described. Chapter 11 was also co-authored by Dr van Loon. We extend our sincere thanks to Dr Kay Price, Kerry Telford, Pam Selim, Sue Eastwood, Shayne Kelly, Natalie Howard, Lois Dennes, Kate Visentin and Peter Jenkin for collaborating with us on the other inquiries we have described in this text. Thank you to Dr Jonathan Crichton and Penny Kearney for their careful reading and suggestions of the analysis processes. The major unnamed contributors are the people who have participated in the inquiries. Their voices are heard throughout.

Preface

This book is the culmination of a ten year research and writing partnership. It has been a joint adventure to consider ways to listen and respond to the voices of people who had previously been silent in health care. We did not conceive of this book when we started to research together, but rather have built our understandings of participatory action research in collaboration with participants. Even after many collaborative research inquiries, we continue to learn. The aim of this book is to create a story 'that is as informed and sophisticated as it can be made at a particular point in time' (Guba and Lincoln 1989:44). Knowing that this story, our perspectives and understandings will change shape as we continue to research, read, listen and learn, we emphasize that this book is a work in progress. We take this opportunity to share our experiences during the last decade and hope that you will feel stimulated to join us toward reform in health care.

About the authors

Tina Koch holds the position of Professor of Nursing (Older Person Care) at the University of Newcastle, Australia. From 1996 to early 2005, she was Director of the Royal District Nursing Service Research Unit, originally a joint chair in Community Nursing with Flinders University of South Australia.

For the past decade Debbie Kralik has researched with people learning to live with chronic illness. The research program has focused on understanding the experience of living with chronic illness and determining ways that people can learn to live well when illness intrudes upon their lives. A theory of 'transition in illness' is in the early stages of development, based on the findings of multiple inquiries. At the time of writing this book Debbie is a Post Doctoral Research Fellow on a Discovery Project funded by the Australian Research Council and jointly administered by the University of South Australia and the Royal District Nursing Service (South Australia). The title of the longitudinal research is 'Transition in Chronic Illness'.

Authorship has been rotated effortlessly and, although we have made an effort to merge our philosophies and positions, incongruence may be observed. Therefore it may be relevant to identify our individual strengths. Debbie's writing identifies most strongly with feminist theories. She leads the discussion on 'transition' and theory development in participatory action research and reflects on the role of the facilitator. Tina is guided by philosophical hermeneutics, but also continues with the debates surrounding rigour in qualitative research, further explores story telling and has developed data analysis frameworks within this text.

We are grateful to our colleagues, Dr Susan Mann and Dr Anne van Loon, whose work has enriched this book. These researchers exude attributes of care and commitment. They remind us that in the process of participatory action, so much depends on these facilitator attributes for making connections with people that have the potential to positively affect change.

1

Introduction

This book is about the use of participatory action research for inquiry and development in contemporary health practice. The aim is to position participatory action research as a vital, dynamic and relevant approach that can be engaged by practitioners and health service providers. Our intention is to emphasize that participating with people is the way to move forward towards sustainable services that evoke human flourishing. We hold strong democratic ideals, whilst at the same time recognizing that naivety cohabits with the desire for reform in health care. If naivety means we are optimistic about the potential groundswell of activity generated by participatory action as people (clients and community) come together to shape, choose and design the health services they want, we celebrate our innocence. Nevertheless, we will articulate some of the issues surrounding participatory action research in health and consider some possibilities for resolution. As with all research methodologies, approaches to participatory action research will vary with the situation and the researcher. The version of participatory action research we present is a hybrid that informs our practice as nurses researching with the community. We draw on our participatory action research experiences to present multiple contexts in our systematic studies that have used observation, the spoken word, written text and electronic communication. Our practical experience stems from our research experiences of undertaking 20 separately funded participatory action research inquiries.

Over the years we have facilitated participatory action inquiries with community members who are professionals, managers, educators and participants. These are men and women using action research to address practical questions in the improvement and development of their practice or their lives. Guided by the work of Reason (1998) we have used action research approaches to explore disruptive events in people's lives and develop ways that people can transition through the event and create a sense of continuity in their lives. Areas we have researched with people include:

- developing of participative problem solving in communities as we agree that 'the political dimension concerns people's right to

have a say in decisions which affect them, and is linked with participatory economics and the development of learning communities' (Reason, 1998, p. 147);

- exploring with indigenous people their stories of living with chronic illness;
- working with people with muted and suppressed voices, such as those living with mental illness or women who were sexually abused as children;
- making contributions to nursing practice and mainstream health care.

Our aim has been to work towards greater participation in health care, so that people can contribute their ideas, and plan and partake in effective action. Our philosophy is grounded in values of democracy, equal opportunities, and education as personal development. We strive to bring issues voiced by participants into mainstream management and to government attention.

We believe that by working together with all stakeholders we can make a difference with people through participatory action research. The ability to make a difference to people's lives has been the major driving force. We view the participatory ethos as taking action towards social change and strongly believe that social justice and equity are enhanced when democratic principles guide our practice and research. Our world-view encompasses 'our total sense of who we are, what the world is and how we know it. It encompasses our sense of what is worthwhile and important . . .' (Heron & Reason, 2001, p. 4). We concur with Reason (1998), who writes that participation is a political imperative because it affirms the fundamental human right of persons to contribute to decisions that affect them:

Human persons are centres of consciousness within the cosmos, agents with emerging capacities for self-awareness and self-direction. Human persons are also communal beings, born deeply immersed in community and evolving within community . . . we are not human without community. Participation is thus fundamental to human flourishing, and is political because, particularly in these times, it requires the exercise of intentional human agency, political action in public and private spheres, to encourage and nurture its development.

(Reason, 1998, p. 147)

What has been noticeable in our experience of the participatory action research process has been the growth and development of all involved. Importantly, our research focus has not always been the identification of and dwelling on issues. Participatory action research principles direct us towards articulating strengths and the dreams and themes of 'what could be'. What is possible for the future is often envisaged through reflection and analysis of the past. We look to the past to identify

strengths and possibilities because people are more comfortable journeying into the future when they carry an understanding of past events and experiences. However, with work in health care environments, nurses, medical doctors and other health care professionals are often driven by a problem-based approach to care. In our search for strengths rather than problems there exists potential conflict. It has been our experience that people who are supported, affirmed and celebrated develop the capacity to move through life's disruptions with greater ease than people who are viewed as having problems or being problematic.

Being involved in the participatory action research process has many benefits as people experience a growth and learning process. Individual and group reform has resulted in human flourishing. Participants have benefited from exposure to the participatory action research process, while researchers have also learned. Participants and researchers together have created and shared a space for working collaboratively in the development of new knowledge. Prolonged involvement with participants over time has ensured that we have listened and learned. Our world-view has enlarged and we too are enriched. Our responsibility as researchers is to share through publication of this book what we have learned.

Chapter 2 discusses the philosophical and theoretical background of participatory action research. In this chapter we describe a chronic illness research programme that has been guided by participatory principles in order to understand how people can learn to live well with illness. Chapter 3 explores the action research process of 'look, think and act' and discusses approaches to data generation. Across all data-generation processes story telling is a central activity in participatory action research.

Chapter 4 begins a comprehensive discussion about participatory action research in practice. We explore the change process using an inquiry as an illustration. This study was initiated by community nursing clinicians who wanted to respond in their practice to the needs of people who were learning to live with the human immunodeficiency virus (HIV) and the intrusion of fatigue. We describe the research process from development of the question, planning the research approach, data generation, and analysis leading to action.

Chapter 5 asks 'What happens when we learn in a participatory action process?' We illustrate and discuss the processes of group interaction by exploring data and our experiences as researchers in two inquiries. One was learning alongside older people with asthma and the other was carrying out research with people living with mental illness who also experienced incontinence. Participants with mental illness were living in boarding houses where incontinence was not tolerated; hence the collaborative development of continence promotion strategies was a challenge. We discuss the importance of context,

and of people using their own knowledge and experiences in the plan for action.

We discuss how the principles of participatory action can frame community health practice in Chapter 6. This requires a shift in the problem focus towards an identification of people's strengths as practitioners work alongside them. The principles of primary health care inform this approach.

The facilitator's role and responsibilities are demonstrated in Chapter 7. We discuss the process of participatory action research and the requirement for the facilitator to be a 'resource' person and catalyst in order to assist participants to define their concerns clearly and then support them as they find their way towards action.

Chapter 8 describes some of the ethical considerations in participatory action research practice. We share the ethical concerns that emerged from two inquiries. One inquiry explored sexuality with women who live with multiple sclerosis. The other was a feminist participatory inquiry that incorporated the use of correspondence (email and letter writing) with women during a 12-month period in order to learn ways in which they incorporated chronic illness into their lives.

Primary health care principles are drivers of community development and capacity building. Two capacity building inquiries are discussed in Chapter 9, with a focus on the development of community partnerships. The first is a participatory action research project with Aboriginal Elders from rural Australia who wanted to develop strategies to bring their plight regarding the high incidence of diabetes to the attention of their community. The second example is an inquiry where we researched with women who were homeless and had been sexually violated as children. The aim was to develop capacity building strategies with these women to promote their strengths.

The aim of Chapter 10 is to stimulate debates about rigour and quality in participatory action research. We consider ways in which participatory action research work may be read as a rigorous approach. At the same time we ask whether participatory action research work is accessible, makes a difference and is sustainable. These are questions about quality. We argue that rigour and quality of participatory action research practice are co-dependent. Guidelines for reading participatory action research inquiries are offered.

There is an absence in action research literature of material for theory building. Our theoretical work on transition may be the exception. Chapter 11 discusses the process of an emerging theory of transition. Transition is a process of convoluted passage during which people redefine their sense of self and redevelop self-agency in response to disruptive life events. Whilst our participatory action research approach is primarily concerned with practical outcomes or change, theory development is a bonus, built through our exposure to the lives of the people with whom we work.

2 Philosophy Underpinning Participatory Action Research

We continue to learn and discover, reflect and make change. Like others in the study it has allowed plenty of debriefing and growth. You can do all the research in the world but without empathy, communication and excellent listening skills it just becomes another paper. You have captured insight into our lives and that came from listening, taking time to hear what we said, allowing us to talk, not belittling us, being non-judgmental, gaining trust and treating us firstly as a person and not a case number or diagnosis.

(Rhondda)

Introduction

This chapter discusses the philosophical and theoretical background to participatory action research. A participatory ethos has driven our research practice and programme. A chronic illness research programme that commenced during 1996 has focused on the experience of long term illness and understanding how people can incorporate the symptoms and consequences of illness into their lives. We have researched with both men and women who have diverse chronic conditions. A primary health care philosophy has underpinned this research programme, which has been undertaken in a community health practice setting. The key aspect of this philosophy has been researching with people; hence we have been guided by the principles of participatory action research. Participatory action research principles enable a potentially democratic process that is equitable and liberating as participants construct meaning during facilitated, group discussions. The excerpt from Rhondda that began this chapter revealed her experiences of participating in research that engaged participatory action research principles. The cyclical nature of the participatory action research process promotes reflection and reconstruction of experiences that can lead to the enhancement of people's lives, at an individual or a community level, or both.

Becoming involved in participatory action research

In an effort to understand and perhaps sequence the events that have led us to participatory action research approaches, we were reminded by van Manen (1996, p. 64) that 'the human science researcher is not just a writer, someone who writes up the research report . . . but . . . rather an author who writes from the midst of life experience where meanings resonate and reverberate with reflective being'. It is not enough to describe life meanings we hear and see, but we recognize that we are situated within our own studied worlds (Lather, 1991). We found it helpful to discuss what had led us to embrace participatory action in our lives:

Tina: What has attracted you to participatory action research?

Debbie: That's a big question! My passion for action research has been fuelled because I have experienced the process as liberating, empowering and educative. I have experienced research processes that have moved people towards reflexivity and new understandings that have brought individuals and communities into policy debate and validated their knowledge. There have been 'turning points' in my life that have led me to literally turn in another direction, toward embracing principles of participation.

Tina: My turning point was when I became conscious of the importance of listening to the stories of patients in the 1980s when I worked as a quality assurance coordinator in a large metropolitan Australian hospital. Since then, looking, thinking and acting with people has been the main motivator in both my professional and personal life. How about you?

Debbie: Well, my personal and professional life are closely entwined, so I find it difficult to talk about them as separate entities. I think I have always had a deep sense of wanting to help. My parents have told me that I had wanted to be a nurse since I was very young. I can recall feeling a little alienated in my teenage years because I did not experience the quandary of deciding what I wanted to do when I left school. Nursing seemed an entirely natural path for me even though I would be the first nurse in our family. More than twenty years later, I am still passionate about nursing. Having said this, I reflect on my earlier nursing years and clearly see my prescriptive approach to care. I was very caught up in the task orientation of nursing. I was always busy and completed more tasks than most. My patients were always spotlessly clean, shaved and nursed in an exquisitely tidy environment . . . even if they didn't want to be!

Tina: The approach to quality assurance, then and now, is largely driven by measurement of patient opinions, staff satisfaction and clinical

outcomes. One measurement instrument in favour during the 1980s was the Rush Medicus Quality Monitoring Tool, which had a specific patient satisfaction component. Every day, as part of the coordinator's role, I would find myself at a patient's bedside with 10–12 randomly-structured questions from the data bank. The kinds of questions asked were: When you first came to the ward, did the nurse introduce herself? When you were first admitted to the ward, did the nurse show you how to find and use the call bell? There was an expectation that the answers to these questions would be yes, no or not applicable, dutifully recorded for further satisfaction analysis. After the patient had completed answering the battery of questions, I would linger at the bedside for a while. Discovering that patients wanted to talk about their experiences, I listened to many stories. It was evident that matters concerning patients were not those that health professionals were intent on measuring. We, as health care professionals, were not really listening to what was important to those in our care. Rather, we imposed our professional views by directing the patient's responses to conform to our quality expectations. I became convinced that working with patients was the key to caring practice and that this could be achieved through listening to their voices in the first instance.

There were similar patterns emerging in our stories. Debbie nodded her head in agreement:

Debbie: I can relate to that. I felt I was a good nurse, and indeed I knew I had a reputation of being a good nurse, an efficient nurse, but I know now that engagement with people had little place in my daily practice. I can also recall times of engaging and connecting with people in my early nursing years and I know I have made a positive difference to many people, but at that time, the tasks of nursing were the priority. They still are in many respects, but I have been enlightened by participatory ways of being with others that have impacted on my nursing practice in positive ways.

Tina: A turning point for me was my PhD inquiry (1990–1993). My study was to describe the experience of being in hospital from the patient's perspective. Emphasis was placed not only on describing the impact of the experience on patients' lives but also establishing what mattered to them about nursing. I believed that the question of what really mattered to them was the most important question to be asked. Immediately there were philosophical and interpretive questions that begged answers. How could I proceed with the inquiry? I decided each of the 14 people engaged in my inquiry would be asked: What are your experiences of being in the acute care setting and what is your story?

Debbie: So why did you turn to story telling and personal narrative?

Tina: In the early 1990s, philosophical hermeneutics was not a topic in the health literature. The interpretive questions which I pondered on for three years were about making sense of these patients' stories. When I asked a patient to tell me about his experiences whilst receiving care, I questioned how I could make sense of his story. I wondered what happened when I emphasized some aspects of his experience and ignored others. I questioned how my interests and values drove the interpretation. That others should be able to trust the accounts I offered was paramount in an era where stories were considered mere anecdote, and qualitative research was lacking in rigour. If validation with my participants had been possible, their stories may have been viewed as legitimate, but collaboratively constructing the storyline was rarely possible. Either these older people were too ill or they had died. So given that co-construction of the story was impossible, how could I re-author their stories? What would make these stories believable? I wanted to tell the story so that each account resonated with the patient's experience, but there were few guidelines to assist with creative writing. Most importantly, how could I tell these stories so that readers would understand what it was like being in hospital? And how could this new understanding enhance the health care we give? Making a difference in health care drives my inquiries. Perhaps naively, I still hold reform incentives. I know that you have similar aspirations.

Debbie: My story is a little different here, but not startlingly so. Clearly our interest in listening to people and being with people pervades. I try to carry my sense of humour on a daily basis and do try to use humour to connect and converse with others. Of course this does not mean I always use humour, even when it would work well . . . just ask our kids and my partner! My partner often says, 'If mama ain't happy . . . ain't nobody happy'. I guess that means I am not engaging and participatory 100% of the time! There have been some significant influences or turning points that have led me towards a participatory action path.

I have been influenced by feminist thought and I like to think my ways of being in the world and the ways I connect with others are framed by feminist ideology. My feminism makes sense to me. By 'my' feminism, I mean my ideas that have been shaped by my 1960s childhood experiences when authoritarian men clearly defined the roles of women within the family unit. However, I come from a family where women who are influential in my life have great substance. From a research perspective, the collaborative approach and focus of consciousness-raising in participatory action are congruent with the feminist principles that I embrace. The partnership that develops between people and me as the researcher is truly a connection

through conversation. Ways of knowing are valued in participatory research as theory is generated from the experiences, lives and understandings of all participants. Participatory research is conducive to the emancipatory goals of feminism because consciousness-raising provides the way in which a greater awareness is achieved and actioned as together we engage in mutually educative and liberating encounters. Without doubt, feminism has shaped my way of being in the world.

Tina: Although we have arrived at similar philosophical positions, we want to connect with people and work alongside them towards reform at individual or community levels, the routes we have taken are quite distinct. My way of being in the world is with less humour. Given my predilection for seriousness, not surprisingly I took a move to the dour and dense intellectual environment of German philosophy. These interpretive readings were given prominence by my need to understand what happens when we listen to others. This meant at first to record my interpretive understandings, and my musings soon began to develop into a strong hermeneutical position. Among the writers who mattered, the work of Gadamer (1976, 1989) was the most appealing. I now recognize that Gadamer's influence on me was decisive. At the forefront was the ontological question of what it is to be a person. By the time I had completed my PhD study, I had delved into existential philosophy and I was beginning to answer some of the interpretive questions posed.

Debbie: How did this impact upon your thinking about being in the world?

Tina: Somewhat hesitantly at first, I saw the world as shaping me and at the same time I was shaping it. Let me explain what I think happens when interpreting. When I ask someone to tell me his story, I accept that it is his interpretation and that it comes from his own life. It comes from his background of understandings. I can make sense of his story only through comparing it with my own experiences and the experiences of others, whether real or imagined. I shape the story and I am shaped by it. A fusion occurs.

Debbie: Do you mean that it becomes a shared story . . . a co-constructed story?

Tina: Let me share an example of co-construction with Albert, an older man who was admitted to the acute care sector. The relationship between us built up over several months. I talked with him every day whilst in hospital and then visited him at his home. The story is created through the dialogue between us. I ask a question, 'What is it like being in hospital?', and I listen in order to make sense of his story. I ask further questions so that I can apprehend. When I leave his bedside,

I have a better idea of what it is like being in hospital, and I write what I have understood. I reflect on the interview process. I may choose to talk with him again, and read out to him what I have understood of his experiences. He responds. As the dialogue continues my understanding deepens. I rewrite the story and ask him again: Is this what it is like? Yes, this is what it is like. The dialogue and writing continues until we are both satisfied.

Debbie: What is to be gained from story telling?

Tina: There are changes in both researcher and participant. I am richer through understanding his story. I have initiated a meaningful relationship. I have gained insight into someone's life and I am changed as a result. I am also concerned because 'his' story is not pretty. The broad scheme of his story hovers on the emotional bankruptcy of caregivers whilst receiving care that makes him feel worthless. We agree that in his situation in a care of the elderly ward, caregivers were careless. However, being engaged in this process, I note that being heard has created in him a sense of worth and a sense of personal power. It seems that the interview process has therapeutic benefits. In the depersonalized environment of the acute care hospital someone was listening. 'I am worth listening to.' I believe the interview process stimulates reflection, and gives people a chance to think about their own situation, and working out what really matters has opened up possibilities.

Debbie: In my work, I have also emphasized that people's stories about their lives and experience should be valued, but it is important to me that the work I do contributes to action that leads to the improvement in the lives of people. A cycle of looking at and thinking about one's situation without some proactive action can be detrimental and disempowering. In my experiences, the changes people have noticed in their lives have not always happened on a large scale, but some people have acknowledged some important changes at a very personal level.

Tina: So far I can see that working collaboratively with our clients, albeit this example of collaboration is based on the dialogue between two people, opens up possibilities. The action you believe should be a consequence of looking and thinking together is not always possible. Albert was prepared to co-construct his story and in so doing he was acknowledged as a person but he did not want to complain about the service. Readmission to that setting was inevitable given his medical condition; he believed he would experience reprisals. On a personal level, being able to tell his story reversed the depersonalization he had experienced in care. There are other ways to act. One is through sharing 'his' story with those working in the depersonalized setting we described. Can the careless care he experienced, as did all the participants in my PhD inquiry, be reformed?

Tina: In the effort to reform, I share the stories of the participants interviewed with those who provide the health care service. Confident that these constructions would offer new understandings about patients' experiences and bring about change, I was dismayed. The realities of working in the acute setting rely heavily on routine and control of patients. When patients' stories reveal that a desire for self-liberation is an aspect of care that is important to them, service providers do not want to hear.

Debbie: Perhaps health workers hear these stories as being disruptive to their practice. Change can disrupt the continuity and certainty of the everyday. It can make us uncomfortable and open us to the scrutiny of others. To really listen to someone's story requires a preparedness to embrace something new . . . to see other possibilities. Is this where recognition of the interplay of power, both organizational and relational, comes into focus? I think this is a considerable challenge for us as action researchers.

In summary, we have noticed that the word 'participation' seems to be often used in the health literature. The merits of participatory action research can vary with both the research situation and the practitioner. At its best, the participatory action research process can be liberating, empowering and educative and can set the agenda for reform and validate the knowledge of participants. It can be a challenge to authentically embrace and practise principles of participation when working within the boundaries of hierarchical organizational structures where information and decision-making are centralized (Winter, 1998). This is often the case for health services. While participation must be central to the research process, it is important that the construct be understood and practised as a genuine process. Participatory action research principles express participation as the central core of health practice as we move from a philosophy of doing things to clients, towards working with people to assist them to identify their own needs and formulate their own strategies to assist in meeting those needs. Habitual ways of working may need to be challenged and questioned so that innovative ways of working with people can be created. The first step is to identify what has been learned through experiences. The process of thinking about learning, the process of reflection, can be a powerful process for building self-awareness and self-confidence. Reflection increases self-knowledge and prepares people to make deliberate, well-informed choices. People engaging with the participatory action research process may find themselves on a route that takes many twists and turns; they may travel along unexpected pathways. It can take time to learn to trust the participatory action research process.

What are the beliefs underpinning participatory action research?

We now turn to the vast literature on participatory action research approaches and identify our theoretical position. As discussed earlier, the philosophy underpinning our approach reflects our concern for the ways in which we can make a difference through participatory action. Working with people to make a difference is a major theme in our work and we view the participatory ethos as facilitating action towards social change. We suggest, however, that the starting point of any inquiry is a systematic reflection on the beliefs and values driving research inquiry. Therefore our account will offer participatory action research as a methodology through describing its philosophical underpinnings and the 'world' in which it belongs.

We have chosen to introduce participatory action research by presenting issues from practice rather than 'schools of thought'; however, it is useful to understand the history and evolution of this research movement. The development of action research has been attributed to Lewin (1890–1947) as the founder of modern social psychology (Marrow, 1969). His favourite dictum was if you want to understand something then try to change it. However, in Lewin's work, participants were not involved in setting the agenda or making decisions. Stakeholders were not seen as active participants in the design of a study. For example, Lewin used action research in his efforts to change people's food habits (Friedlander, 1982).

'... action research is a participatory, democratic process concerned with developing practical knowing in the pursuit of worthwhile human purposes ... It seeks to bring together action and reflection, theory and practice, in participation with others, in the pursuit of practical solutions to issues of pressing concern to people, and more generally the flourishing of individual persons and their communities.'

(Reason & Bradbury, 2001, p. 1)

Participatory action research emerged in the latter half of the twentieth century. Paulo Freire (1970), one of the world's leading educationalists, in his classic text *Pedagogy of the Oppressed* broke with the tradition of gathering data on oppressed people and instead carried out research with participants, placing capabilities in the hands of disenfranchised people so that they could transform their lives themselves. It should be noted that the methodology Paulo Freire developed was considered a threat to the established order and he was forced to leave Brazil for 20 years. In his time, however, he helped

to empower countless impoverished and illiterate children. Claiming that the authoritarian teacher-pupil model failed to develop people's critical awareness he advocated an education programme based on the actual experiences of students and on continual shared investigation. Those 'learning to read and write come to an awareness of self-hood and begin to look critically at the social situation in which they find themselves' (Freire, 1970, p. 11). He argued that every person, no matter how impoverished or illiterate, can develop self-awareness, which will free them to be more than passive objects in a world in which they have no control. Often students take the initiative to transform a society that has denied them the opportunity of participation. Freire (1970) provided evidence that through working collaboratively with people this new awareness of self frees people to respond actively to change. Freire's methodology based on collaboration has had major implications for research and education in health care.

The terms collaborative inquiry and participatory action research are often used interchangeably in our work; in fact, we prefer to use the term collaborative inquiry or participative inquiry instead of participatory action research. Let us explain.

There are many forms of inquiry that are participative, experiential and action oriented (Reason & Bradbury, 2001). The action research 'family' includes a whole range of practices and approaches and the assumptions unpinning these are diverse in political, psychological and philosophical orientations. In presenting our version of practising participatory action research we draw on three orientations.

In the first version (Gustavsen, 2001), action research is the mediating discourse where the core contribution of research is 'to create relationships between actors and arenas where they can meet in democratic dialogue'. A second interpretation (Orlanda Fals Borda, 2001) explained that the tensions between theory and practice are resolved on the basis of a philosophy of life 'committed to social renovation for justice', whereas the third (Pasmore, 2001) links social and technical perspectives. Pasmore (2001) argued that new ways of thinking about research can 'challenge the dominant paradigm in research institutions, organizations and society'. We are aware that those who favour the dominant medical paradigm in health research challenge the legitimacy of participatory action. We are, however, committed to a just society and our intent is to create democratic dialogue and reform through bringing people together in a safe place. To achieve this, we are guided by social sciences and critical social theory.

Social sciences and critical social theory have provided insights from Freudian (and post-Freudian) psychology and Marxist theory. Critical theory informs a range of approaches, of which participatory action research is one, and raises critical questions about the conditions

that sustain those forms of social life that are experienced as problematic by particular groups of people. The concept of hegemony (Gramsci, 1971) is important to this approach in participatory action research. The argument is similar to that of Freire cited earlier; that it is only through awareness of the ways in which people contribute to their own oppression that people can begin an empowerment process. Empowerment of people is a desirable outcome of the process of constructing and using their own knowledge.

Knowledge generation is an important aspect of the theory and practice of participatory action research. People are enabled to see the ways in which the establishment monopolizes the production and use of knowledge. This is the meaning of consciousness raising or conscientization, a term popularized by Freire (1970). Freire's approach included learning to do by doing it. Valuing people's knowledge sharpens their capacity to conduct research about their own interests, and helps them to appropriate knowledge produced by the dominant knowledge industry for their own interests. Most importantly, it allows issues to be explored from their perspective (Reason, 1994). Hence our concern with listening to people's voices or stories is a starting point for participatory action research inquiry.

Some participatory action research approaches prioritize working with oppressed groups of people, whose issues include inaccessibility, colonization, marginalization, exploitation, racism, sexism and cultural disaffection (Hagey, 1997). Utilizing a participatory action research approach within this context is explicitly political when the aim is to restore to oppressed people the ability to create knowledge and practices which are in their own interests (McArdle & Reason, 2006). The intent of participatory action research is to accent the processes of collaboration and dialogue that empower, motivate, increase self-esteem and develop community solidarity (McArdle & Reason, 2006).

We have not usually aimed to adopt this larger social reform agenda as the main objective in our research. Our participatory action research group participants often include people who live on the fringes of society; our inquiries with homeless people come to mind, but we also research with people who are comfortably middle class. Although people we research with often live with chronic illness, where possible the research focus has not been specific to a medical diagnostic group but rather related to people's own construction of illness and the way it impacts upon their lives (Kralik et al., 2001b). Nevertheless, we acknowledge the work of participatory action research researchers who research exclusively with oppressed people and whose role is to actively encourage people to uncover the ways in which the establishment monopolizes the production and use of knowledge in an attempt to unveil power relations.