

Participatory Action Research: General Principles and a Study With a Chronic Health Condition

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The construct of participatory action research (PAR) has been gradually gaining recognition in the social sciences as a promising strategy for actively involving research participants in the development and implementation of the research process while attempting to pursue socially relevant research issues. A central characteristic of PAR is that it not only aims to empower individuals, but more important, it aims to facilitate higher order social, organizational, or political change (Reason & Bradbury, 2001). The authors of this chapter have used this research approach with people with disabilities in the context of promoting businesses' accessibility compliance with the Americans With Disabilities Act in minority communities (Kaplan, Hernandez, Balcazar, Keys, & McCullough, 2001); developing and implementing a peer-mentoring model for individuals with violence acquired spinal cord injuries (VASCI; Hernandez, Hayes, Balcazar, & Keys, 2001); and developing and implementing a model to empower individuals with chronic fatigue syndrome (CFS; Taylor & Jason, 2002).

PAR combines social investigation, education, and social action to define and address social problems, particularly among disenfranchised and oppressed groups (Brown & Tandon, 1983). It is both a research ideology and a strategy for conducting research. As an ideology, PAR represents a set of beliefs regarding the role of social science research in alleviating social injustice and promoting community involvement in social change efforts. PAR offers specific guidelines for planning and implementing research projects (Tandon, 1998). The approaches involving participatory research emerged from the need

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of oppressed populations to empower themselves by participating as partners, and in some cases, key directors of various aspects of the research process, thereby generating sociopolitical awareness and mobilizing to effect larger social and systemic change. Participatory action research provides a framework by which people with disabilities can take an active role in designing programs, conducting research, and reestablishing power and control over their own lives (Balcazar, Keys, Kaplan, & Suarez-Balcazar, 1998). Most individuals with disabilities have faced tremendous oppression through social stigmatization, discrimination, and the loss of political and economic resources (Block-Lourie, Balcazar, & Keys, 2001; Charlton, 1998). This chapter provides an overview of key conceptual issues associated with PAR, a brief review of the principles for PAR implementation, and a field research example with individuals with CFS. Readers interested in more extensive reviews of PAR are encouraged to read Selener (1997), Reason and Bradbury (2001), and Whyte (1991).

Definitions of Participatory Action Research

The particular form that the PAR process actually takes depends on the context of the research. The defining factor is the degree of power (control) that the constituents of the study have over the process. Danley and Langer-Ellison (1999) suggested that we can think of a continuum of power held by researchers and research participants that goes from little power to full power or control. At the low end of the spectrum are advisory committees, which are sometimes called PAR because research participants have some involvement but ultimately very little power or authority over the project. On the other end, participants have full control over the research process, including hiring and firing authority over the professional researchers. Midpoints on the continuum may include hybrid projects in which research participants have a high degree of control over the research process but professionals are responsible to outside funding agencies and thus retain decision-making authority over some areas. Table 1.1 provides an overview of the research participants' roles in the PAR implementation process provided by Phillips-Tewey (1997). The participants' roles are classified on the basis of three criteria: the degree of control that participants have over the research process (Litvak, Frieden, Dresden, & Doe, 1997), the extent of collaborative decision making between participants and professional researchers (Turnbull & Friesen, 1997), and the levels of input from and commitment of participants with the research process (Gordon, 1995).

There are also variations of PAR based on *its purpose*, which can influence the conceptualization and direction of the study. The first was represented by Whyte (1991) and reflects an organizational perspective influenced by the sociotechnical systems approach to organizational behavior and by social research methodology. Whyte (1991) defined PAR as a "powerful strategy to involve practitioners in the research process from the initial design of the project through data gathering and analysis, to the final conclusions and actions arising out of the research" (p. 7). From this perspective, members of the organization become actively involved in the quest for information and ideas

Table 1.1 The Continuum of Participant Involvement in PAR Implementation

Level of PAR	Degree of control	Amount of collaboration	Degree of commitment
No PAR	Research participants with no control	Minimal	None
Low	One consumer adviser Group of consumer advisers	Advisory board members	Minimal
Medium	Responsibility for oversight and representation in research meetings	On-going advisers Reviewers Consultants Possible contractual agreement	Multiple commitments Increased ownership of the research process
High	Equal partners Leading partners with capacity to hire the researchers	Active researchers Research leaders	Full commitment Full ownership of the research process

to guide their future actions. The purpose can be to *improve efficiency or effectiveness* in a particular operation, to *improve quality*, or to *develop new products*.

The second approach was presented by Selener (1997) and reflects the view of the methodology as *an instrument for social change in the struggle against oppression*, influenced by Paulo Freire, Orlando Fals Borda, and other developing-world social researchers. Selener (1997) defined PAR as “a process through which members of an oppressed group or community identify a problem, collect and analyze information, and act upon the problem in order to find solutions and to promote social and political transformation” (p. 17). A form of compromise between these two positions is the definition offered by Elden and Levin (1991), who defined PAR as “a way of learning how to explain a particular social world by working with the people who live in it to construct, test, and improve theories about it, so they can better control it” (p. 131). The authors are interested in generating theories that help people learn how to better control the circumstances of their lives, through a process they characterize as “learning for empowerment and democratization.” This definition suggests a focus on empowerment as a way to increase people’s control over relevant aspects of their work or living environments. They also imply a belief in the people’s capacity to participate in the research process. This is the perspective that seems closer to community psychology and will be the one guiding our analysis.

Epistemological Assumptions in PAR

An important and innovative component of PAR is its capacity to empower participants with learning. Elden and Levin (1991) argued that PAR as learning can empower in three ways: First, because of the specific insights, new understandings, and new possibilities that participants discover in the process of creating better explanations about their social reality, they become empowered. Such awareness changes the way people see themselves and their human potential.

Second, by engaging in PAR, participants learn how to learn. People who have a history of marginalization or have simply been ignored often feel insecure about themselves and their own knowledge. To complicate matters, typical schooling experiences are rarely conducive to instilling a passion for learning and self-discovery of new understandings. Students are primarily asked to regurgitate content out of context with the intention of meeting some arbitrary test standards. So often people do not know how to learn and PAR offers them an opportunity to learn from each other and to enhance the understanding of their own social reality by engaging in intense dialogue with each other.

Third, PAR can empower when participants learn how to transform their own social reality. In this case, knowledge becomes social praxis. This learning is in effect what Freire (1970) characterized as the necessary step to comprehend one's potential to act to transform the world. Therefore, the process of learning becomes a process of taking control conducive to transformative action.

Selener (1997) suggested that thinking, feeling, and acting are ways of knowing. He argued that traditional scientific methods rely exclusively on cognitive activities as a source of knowledge. Earlier, Lewin (1948) had identified feeling and acting as ways of knowing. He acknowledged that when the feeling and acting dimensions of learning are ignored, we are left with a limited view of human beings and their capacity to learn. Participatory action researchers argue that thinking, feeling, and acting are three integrated aspects in the process of creating knowledge. The subjective (captured through qualitative research) becomes a necessary part of the process of understanding social reality. Elden and Levin (1991) argued that those who spend their work lives in a particular organization or those who live in a particular community get to know more about it and have more ways of making sense of their world than would be possible for any outsider to appreciate. It follows that the best way to access such knowledge is through dialogue, allowing individuals to share their views in a free and supportive context.

Practice Should Inform Theory and Vice Versa

Theory without links to empirical data is likely to be sterile, and similarly, methodology without any guidance from theory is bound to be unproductive. It is recognized that some hard-nosed scientists reject qualitative data and field observations as being simply "storytelling." On the other hand, it is hardly scientific to accept measures of behavior simply based on what people say about what they do. No matter how many sophisticated quantifications are made with most survey results, the source is still subjective.

PAR proposes to measure interactions and actions that are indeed much more difficult to assess than attitudes or opinions. Most PAR projects are interested in measuring outcomes: What are the specific changes resulting from the research process? What changes in the degree of control (empowerment) participants experienced as a result of the research? Theory in the context of PAR is built on the accumulation of knowledge based on repeated field experiences (Park, 1993). It is experiential knowledge that accumulates and combines to improve our understanding of the way a particular organization or community functions. Such theory reflects the nature of the interactions and activities under study, considering the contextual and personal factors that intervene in the process. The theories may help explain interactions and in some cases even predict certain outcomes based on past experiences. In our opinion, this is a rich approximation to the phenomenon under study.

Redefining the Researcher's Role as a Catalyst for Social or Organizational Change Carried Out by the Research Participants

Elden and Levin (1991) proposed that empowering participation occurs between insiders and outsiders in what they call cogenerative learning. This implies that both groups operate out of their initial frames of reference but communicate at a level where old frames can be changed and new frames generated. The insiders are not simply sources of data but they actively help create new meanings for the information generated in the research process; they become cocreators of knowledge (Elden & Levin, 1991). This process improves as the research process advances and participants gain experience. On the other hand, it is important to remember that the insiders carry out the actual change, and the outsiders only play a supportive role. Montero (in press) repeatedly reminded us that the role of the outsiders in the social transformation process is not to lead but to support. The professionals are not the liberators; they are merely the facilitators in a struggle in which people seek to liberate themselves.

Relevance of PAR to Community Psychologists

PAR is taking a central role in the field of community psychology. This is an approach that is not only consistent with our values and philosophy but our methods too. Some of the reasons follow.

CITIZEN PARTICIPATION IS CENTRAL TO COMMUNITY PSYCHOLOGY. Wandersman, Chavis, and Stucky (1983) advocated that involving citizens as partners in the research process is fundamental to ensuring that the research is responsive to their needs and values. In addition, they suggested that such a collaborative effort can improve the quality and applicability of the research, encourage public support for its findings, enhance the potential for use of research results, and serve to empower citizens by increasing their sense of control over their lives. Kelly et al. (1988) explained how citizen participation is essential for the research activity to be ecologically relevant, understood, and valued by the community members.

SOCIAL CHANGE IS A DESIRABLE GOAL TO COMMUNITY PSYCHOLOGY. Heller, Price, Reinhartz, Riger, and Wandersman (1984) argued that social change is a pervasive condition in the world and multiple factors, such as diverse populations with diverse and multiple needs, declining resources, growing demands for service accountability, expanding knowledge and changing technologies, economic changes, community conflict, and dissatisfaction with traditional approaches to deal with social problems could lead the list of reasons for change. Community psychologists deal with these issues, and PAR is one strategy to pursue such change.

PAR OFFERS COMMUNITY PSYCHOLOGY A METHOD OF RESEARCH AND ACTION. Selener (1997) offered methodological guidelines for conducting PAR. These include the initial stages of organizing the research project and gathering knowledge of the community or organization, the process of defining and critically analyzing the problem, and defining a plan of action. Balcazar, Seekins, and Fawcett (1985) developed an action guide to help individuals engage in community change, which was later adapted to guide community health change efforts (Altman, Balcazar, Fawcett, Seekins, & Young, 1994). Balcazar, Keys, and Suarez-Balcazar (2001) also developed a guide to community capacity building that incorporates the Community Concerns Report Methodology (Fawcett, Seekins, Whang-Ramos, Muiu, & Suarez-Balcazar, 1987) and specific strategies for community organizing and leadership development.

PAR INCREASES COMMUNITY PSYCHOLOGISTS' OWN CRITICAL AWARENESS AND COULD LEAD TO RADICALIZATION. In the case of PAR applications toward community change, the researcher often finds him- or herself in conflict with his or her own class interests. This conflict can lead the researcher to raise some basic questions about his or her position of privilege and his or her role in society (Fals Borda, 1994). Prilleltensky (1994) argued that if psychologists are going to become a vehicle for conscientization for other people, we should be the first ones to subject ourselves to this very process. In PAR, the researcher becomes involved in developing community members' capacities for collective identification and analysis of problems and the implementation of solutions. This may place the researcher in conflict with people who may not be willing to relinquish their power. Although conflict can sometimes be avoided through compromise, it is often an integral part of the process of power redistribution.

General Principles for Implementing PAR in Community Research

Consider participants as social actors, with a voice, ability to decide, reflect, and capacity to participate fully in the research process. This principle recognizes the central role that participants play in the research process and to their capacity to do so. It implies minimal biases from the external agent toward the people's capacity to become successfully involved. It also implies the need to change the way we train researchers on how to conduct community and organizational research. Kelly et al. (1988) pointed out how the extent of citizen

participation is the fundamental criteria to determine whether community research will be implemented and have an impact. Brydon-Miller (1993) illustrated how a small group of individuals with physical disabilities working with the researcher organized to improve the accessibility at a local shopping mall. They obtained the appropriate regulations under the Americans With Disabilities Act and used them to press their case successfully.

The ultimate goal of PAR is the transformation of the social reality of the participants by increasing the degree of control they have over relevant aspects of their community or organization. The principle implies that empowerment is the ultimate objective of the PAR process and therefore its attainment has to become an explicit part of the purpose of any action. Hernandez, Hayes, Balcazar, and Keys (2001) described a PAR approach designed to use peer mentors to help recent victims of gun violence who become paralyzed set and pursue goals in their rehabilitation process. The peer mentors became role models to their mentees and showed them the life options and opportunities available to them after the injury. Mentees were encouraged by their mentors to take control of their rehabilitation process and become independent. Preliminary results suggest that peer mentors can help their mentees attain personal goals by providing information and direct assistance in the process.

The problem originates in the community/organization itself and is defined, analyzed, and solved by the participants. The external agent's role in this case is that of facilitating the dialogue among community members to develop consensus over the specific target of the study. Helping people realize that they are the ones who can solve their own problems is not easy. Most people are skeptical and insecure about their capacity to change their social reality (Freire, 1970). Balcazar, Seekins, Fawcett, and Hopkins (1990) implemented an advocacy training program to help a small group of people with physical disabilities identify issues and implement actions to address those issues. Participants were successful with approximately 60% of the issues identified, improving the accessibility and the quality and types of services available to people with disabilities in the community.

Active participation leads to a better understanding of the history and culture of the community/organization and a more authentic analysis of the social reality. This process allows for a more accurate appreciation of the issues and challenges experienced by the participants. External agents can never achieve a full understanding of the nature of the organization or community without an authentic dialogue with community members. Bartunek, Foster-Fishman, and Keys (1996) conducted a series of qualitative interviews with several individuals with developmental disabilities, family members, service providers, and professionals with the purpose of documenting the development of a support and advocacy group for individuals with developmental disabilities. Participants offered their perspectives about the history of the process, including the individual and organizational support, as well as the cultural shift that led to the creation of the organization.

Engaging in a dialogical approach also leads to critical awareness. The dialogue with community or organizational members can give researchers not only a more accurate understanding and appreciation of the reality of the community or the organization but a more critical understanding of the social

reality to participants. Dialogue can lead participants to reflect on their history and the factors that maintain their condition of oppression or exploitation. This reflection can in turn lead people to move away from a passive perception of victimization to a perception of actors responsible for forging their own future. Balcazar et al. (2001) described their work with a group of immigrant Latino parents of children who are deaf. The parents were associated with a local agency that was not responding to all of their needs. Their involvement in the research process led them to become critically aware of their situation and especially of their own capacity to act. They left the agency and started their own organization, providing services and supports with volunteers to approximately 60 families.

Recognizing people's strengths also increases their awareness about their existing resources and mobilizes them to help themselves. This principle is also commonly used in community research. Building from strengths reinforces people's capacity to act. Very often community members and employees do not have an awareness of the latent resources available among them. Balcazar, Mathews, Francisco, and Fawcett (1994) documented the actions and outcomes of four advocacy organizations of people with disabilities. The advocacy training process helped the groups identify and build strengths and resources, which were later used to promote their agenda. Perceptions of people with disabilities often focus on their shortcomings, and such negative perceptions are often internalized. Taking actions to transform their community and succeeding led in turn to a revaluation of their abilities and potential.

The research process also promotes personal change both for participants and researchers. PAR is a transformative experience in the sense that the dialogue and the process of analysis of the social reality lead participants to question their own roles and responsibilities toward social change. Engaging in true dialogue is a transforming experience. It is a process of mutual discovery that leads one to rediscover who we are and why. PAR often leads participants to question their motives and to overcome their fears and perceived limitations. It is a liberating process both for the insiders as well as the outsiders. Balcazar et al. (1990) reported how several of the participants in the advocacy organization changed their perceptions about their own abilities and their personal effectiveness. For the researchers, the experience led them to a sustained effort to replicate and disseminate the advocacy training materials and procedures among several groups of people with disabilities from around the country. For example, in the state of Idaho, a statewide coalition of individuals with chronic mental illnesses and family members from the Alliance for the Mentally Ill (AMI) was organized using the advocacy-training model. The process was replicated using a train-the-trainer approach, resulting in more than 150 individuals being trained over a period of four years, transforming the parent and consumer involvement in issues related to mental health in the state.

To conclude, PAR allows people with disabilities to shape the research process to meet their needs and to direct the research process toward the generation of desired outcomes. The research endeavor becomes a process of social renovation or transformation. Issues associated with physical accessibility, quality and availability of services, community attitudes or discrimination against people with disabilities are attended to. Consumers move from a passive

victim stance to a proactive citizen-with-rights stance. Once they have made this transformation, they can no longer be victimized without a fight.

The following section presents a community-based action project that applies PAR as a paradigm for empowering individuals with chronic fatigue syndrome, an emergent disability that is new to the independent living movement.

Case Study: PAR Applied to Chronic Fatigue Syndrome

Chronic fatigue syndrome (CFS) is a highly debilitating condition characterized by six or more months of medically and psychiatrically unexplained, persistent fatigue and four or more of the following symptoms for at least six months: impaired short-term memory or concentration, sore throat, tender lymph nodes, muscle pain, multijoint pain without swelling or redness, new-type headaches, unrefreshing sleep, and postexertional malaise for ≥ 24 hours (Fukuda et al., 1994; Holmes et al., 1988).

CFS has been recognized as a disability under the Americans With Disabilities Act (ADA; Banks, 1993) and legitimated as a medically determinable condition by the Social Security Administration (Social Security Ruling 99-2p, 1999). Despite these developments, individuals with CFS continue to report negative experiences with service providers characterized by outright disbelief, lack of knowledge or understanding of CFS, overemphasis on psychological or psychosocial explanations, and a general lack of responsiveness or treatment planning (Anderson & Ferrans, 1997; Banks & Prior, 2001; Green, Romei, & Natelson, 1999). Perhaps as a result of this tension, people with CFS report a lack of social and public support and tend to underuse rehabilitative services and community-based resources traditionally available to individuals with other disabling conditions (Jason, Ferrari, Taylor, Slavich, & Stenzel, 1996).

Traditional medical and psychological treatment approaches for individuals with CFS have demonstrated contradictory outcomes and remain in an experimental phase of development (Taylor, Friedberg, & Jason, 2001). It is possible that empowerment-oriented support efforts emphasizing the integration of public and private community-based service systems, peer counseling, advocacy, civil rights, and education may offer effective means of supplemental support for individuals with this syndrome. For these reasons, Centers for Independent Living offer a most appropriate avenue for resource acquisition and coordination for individuals with CFS.

Centers for Independent Living epitomize the concept of community participation. They are community-based, empowerment-oriented organizations that are operated by and for individuals with disabilities, endorsing the concepts of freedom, choice, and control. The independent living philosophy locates many of the problems for people with disabilities within society and in its environmental barriers, discriminatory acts, and socially stigmatizing attitudes. According to this externalizing orientation, the main objective is to break down societal barriers, allowing people to integrate themselves fully into the community in an effort to be treated equally.

The CFS Empowerment Project, funded by the National Institute on Disability and Rehabilitation Research, was designed to provide individuals with CFS entry into Centers for Independent Living, and an opportunity to struggle with and incorporate relevant aspects of the independent living philosophy, such as learning self-advocacy and empowerment. Until this project began, few people with CFS were aware that Centers for Independent Living existed, and even fewer felt entitled to seek support from these centers. This project was initiated through one such center, Access Living of Metropolitan Chicago, a cross-disabilities organization that outreaches to underserved populations and individuals with emergent disabilities.

Additional aims of the project include improving quality of life; symptom management skills; and resource acquisition by offering peer counseling groups, one-on-one mentoring in self-advocacy, and ongoing consultation and economic support for resource acquisition while following a PAR approach. Participant-centered goal setting serves as the linchpin of the program. It is woven into both the group phase and the one-on-one phase of the project to contribute to participants' empowerment and facilitate relevance of the program for participants on a more individualized basis. A collaborative process allowed for the researchers, the peer counselors with CFS, and the staff of Access Living to iron out disagreements involved in integrating the agenda of the participants and peer counselors with CFS with the ideology and practices of the independent living movement. The CFS community has not historically seen themselves as members of the disability community but rather from a medical model perspective as sick. Through this project we worked to change the paradigm about how individuals with CFS view themselves.

Step 1: Planning the Project

An extensive amount of participation was elicited from the CFS community as well as from the staff of Access Living, the Center for Independent Living, during the initial steps of project planning. A number of professionals and community members who have CFS or are closely connected with an individual with CFS contributed to the design and development of the project and grant proposal by providing the principal investigator with consultation regarding a number of pragmatic aspects of the project, including the structure of the program (e.g., the need for both group and one-on-one contact), the pacing of the program (e.g., biweekly groups rather than weekly groups), the location of the program (e.g., need for a chemically and environmentally safe setting), the need for personalized transportation to and from the program site to maximize the opportunity that even the most disabled individuals with CFS would attend, and the need to provide reasonable access to key resources, such as personal assistance with activities of daily living, housekeeping, low-cost accessible transportation, subsidized housing, affordable legal assistance, energy assistance, and vocational rehabilitation services. Staff of the Center for Independent Living provided suggestions and advice about how to position the program within the center to best facilitate the transfer of knowledge and expertise about CFS from the peer counselors and program participants to the other

staff members at the center for independent living. The goal of having the program offered through the Center for Independent Living was to provide a natural structure within which to sustain the program over time in the absence of support from the research staff.

Step 2: Implementing the Program

Part 1 of the program involved peer counseling groups. In accord with the empowerment-oriented model of PAR, the peer counselors with CFS conducted one 2-hour focus group with participants as the first of eight peer counseling sessions that occurred biweekly over a period of 16 weeks. During this focus group, members introduced themselves and provided background information about their experiences with CFS and about what they hoped to accomplish as a result of participating. This process enabled members to establish rapport, select goals, and construct an individualized goal plan with assistance from the peer counselors (as needed). This individualized goal plan allowed participants to delineate goals they then addressed during the program period. In addition to the goal plan, peer counselors provided an overview during this focus group of major themes relevant to resource acquisition, advocacy, and CFS management that could be covered in the seven group sessions to follow. Participants then selected seven of these topics from a list of educational themes previously identified as a result of the needs assessment (Jason et al., 1996) and recommended by other consultants with CFS as most pertinent to the resource needs and quality of life of individuals with CFS.

The themes (potential group topics) included (a) developmental stages of living with CFS (Fennell, 1995); (b) activity pacing using the Envelope Theory (Jason et al., 1999); (c) skills to manage physical and cognitive symptoms of CFS independently (Friedberg & Jason, 1998); (d) economic self-sufficiency (e.g., obtaining public assistance with electricity needs, transportation needs, and personal assistant needs and obtaining social security and disability income); (e) employment issues (e.g., issues related to the ADA and workplace accommodations, vocational rehabilitation, and modifying employment); (f) personal relationships (partner, family, friends, coworkers, employers, etc.); (g) relating to medical providers; (h) medical approaches and current medical research on CFS; (i) alternative medical approaches; (j) relaxation and meditation; (k) journal writing; and (l) nutritional approaches. After voting and selecting seven of these topics, members were then encouraged to select areas of more specialized focus within each of these major themes according to their individualized needs and goals for the program.

Once members decided which areas to focus on within each of the seven themes, members shared and discussed their experience and knowledge in each of these areas. Members with particular experience or expertise in one of these areas were encouraged to prepare a presentation on that area for the group session dedicated to that theme, again consistent with the ideology of PAR fueling this project.

Following the initial focus group, a series of seven peer-facilitated group sessions occurred biweekly over a 14-week period. The emphasis of the first

60 minutes of group focused on goal setting, with each member revising and reporting on attainable objectives and goals using her or his own individualized goal plan and receiving feedback from peers in overcoming any obstacles they faced. The second 60 minutes of group involved an educational presentation on one of the seven topics, and reflections and feedback were gathered at the end of each group. In many cases, the peer counselors or participants served as the lecturers. This process promoted maximal participation in the research process on the part of participants, a key point when implementing PAR (Bradbury & Reason, 2001). The end-of-group reflections form was administered at the end of each group. This form was designed to allow participants to provide direct feedback to the peer counselors regarding their opinions of the quality and practical relevance of each group. Suggestions and feedback were then incorporated into the continued implementation of the project, increasing the ecological relevance of the program and allowing participants additional control over the process of program development and research. In addition, the form was designed to assess the relevance of each group to the concepts of empowerment, sense of community, advocacy, and the independent living philosophy. This allowed for an indication of whether participants would be willing to act on what they learned in the process of the research, a reflexive concern for practical outcomes that is essential to the PAR process (Bradbury & Reason, 2001).

SELF-ADVOCACY TRAINING/ONE-ON-ONE PHASE (PART 2 OF THE PROGRAM). Part 2 of the program, the one-on-one phase, involved peer counseling and self-advocacy training. To manage CFS, many individuals require supportive services (e.g., peer mentoring, social services, professional counseling to facilitate adjustment to disability, assistance in developing activity management strategies, vocational counseling, occupational and physical therapy, and personal assistance/housekeeping services). Through self-advocacy training and case coordination services available through Access Living, participants were provided with the training, skills, knowledge, and financial support to create their own linkages to supportive services during this period. Each participant also engaged in self-advocacy training and role playing according to a help-recruiting model previously used by Balcazar, Keys, and Garate-Serafini (1995). This training program was designed to assist adjudicated youth with disabilities to attain their personal and rehabilitation goals, and it corresponds with goal-setting methods typically used in action plans to facilitate goal attainment during community-based programs (Balcazar et al., 1995).

RESOURCE FUNDS (USED THROUGHOUT PARTS 1 AND 2 OF PROGRAM PERIOD). Resource funds were provided to each participant in an amount of \$300 during the entire program period to support services and resources needed by participants to accomplish the objectives listed on their goal plans. Participants were empowered to use these funds for a variety of purposes, provided that the use of the funds enabled them to accomplish one or more of their set goals. Actual use of the funds ranged from covering the cost of a job seminar for a participant seeking to become re-employed, to covering the cost for ergonomically designed furniture and other adaptive devices to reduce pain while performing common

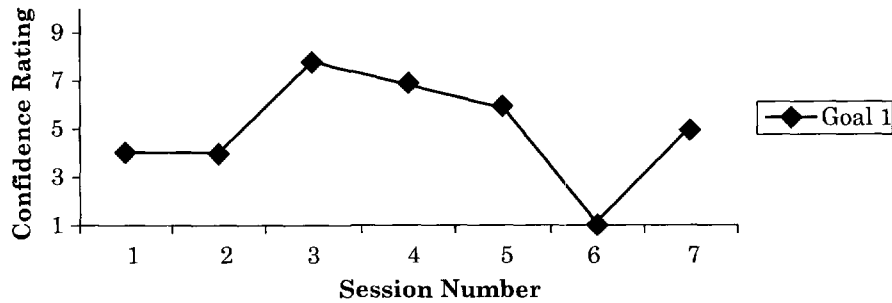


Figure 1.1. Goal 1: Obtain disability insurance benefits.

activities of daily living. The funds were also to be used to allow participants to sample certain services to maximize independence, such as hiring a personal assistant to help a participant to accomplish activities of daily living (e.g., doing dishes, paying bills, grocery shopping, preparing food, keeping up with housework).

Participant's Perspective

The following section presents time-series data regarding specific goals selected by one of the participants during the group phase. For each goal, confidence ratings ranging from 1 (low) to 10 (high) were charted over a seven-session (14-week) period to reflect the level of certainty the participant felt about each session with respect to meeting the objectives required to accomplish her goal by the end of the group phase. In addition to data related to goals, the participant's reflections regarding empowerment, the independent living philosophy, CFS advocacy, and sense of community are presented and discussed. Identifying details about the participant have been altered to protect her confidentiality.

This participant was a woman newly diagnosed with CFS following an episode of infectious mononucleosis who had been forced to take a four-month leave of absence from her work before the program. During the program, she had managed to work full-time for five months. Her goals for the program revolved around ensuring her own economic self-sufficiency, managing CFS symptoms, and locating and accessing various health care professionals. During the group phase, the participant rated her confidence regarding the ability to accomplish each goal on a scale of 1–10, where 1 indicated expected failure and 10 indicated expected achievement. Figures 1.1 through 1.3 summarize the participant's confidence ratings of goal attainment reported during the group sessions.

Based on her confidence ratings, which corresponded to qualitative data reported during the groups and written on her goal plan, it is clear that this participant made significant progress toward two of her three goals. With respect to her first goal, the participant was neither as confident nor as successful with respect to obtaining disability insurance benefits. In part, this was due to the fact that she became re-employed during the program and was

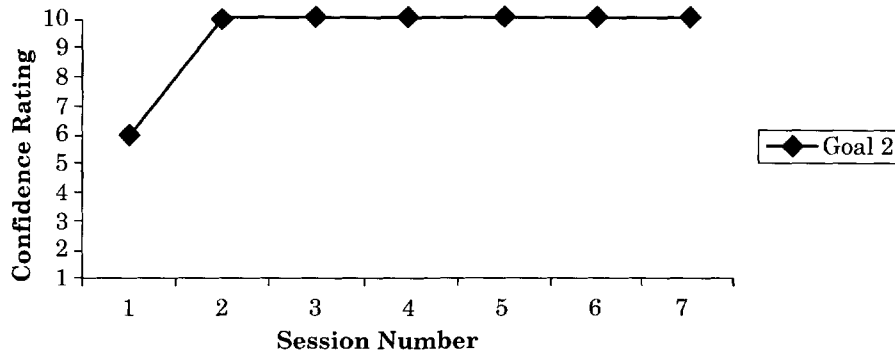


Figure 1.2. Goal 2: Improve management of CFS symptoms.

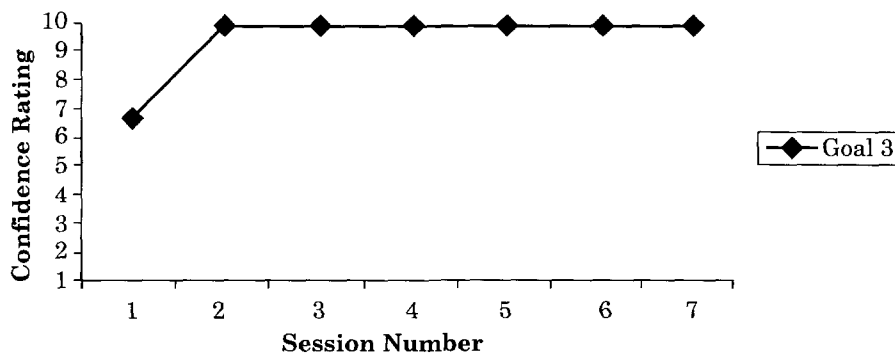


Figure 1.3. Goal 3: Locate and consult with health care professionals to assist in managing CFS.

attempting to apply retroactively for coverage to which she had been entitled but never received. Although she was able to obtain the necessary information from her long-term disability insurance company regarding reasons for denial of coverage and was able to obtain information regarding resources to assist her with the appeals process, she became overwhelmed by the inaccuracies cited by the insurance company as reasons for her denial of coverage. In addition, because she began to feel significantly better during the program period, she reported feeling more financially secure and stated she was unsure as to whether she would appeal the decision of the insurance company regarding the period in which she took the leave of absence. However, she felt the appeal might be worth pursuing as a matter of principle. The participant experienced the most difficulty and the least confidence in obtaining this goal because she felt that the external barriers imposed by the insurance company would

outweigh her own efforts to appeal the decision. Thus, the outcome regarding this goal was not solely within her control.

In terms of the second goal of managing CFS symptoms, the participant's confidence ratings reached the highest possible rating in Session 2, and she was able to maintain that confidence and work toward her objectives throughout the group phase. Specifically, she incorporated many aspects of the educational components covered during group training into her symptom management regime, including principles of activity pacing and energy conservation, empowerment and self-advocacy in her employment setting, learning how to reframe negative self-statements and manage perceived criticism from others, sleep hygiene techniques that included establishing a regular sleep-wake routine, and relaxation-meditation skills.

Regarding her third goal of locating and consulting with health care professionals, the participant consulted with a number of health care professionals to supplement her use of the information she learned during group training. She consulted with a primary care physician, a nutritionist, a psychotherapist, a massage therapist, and an allergist. She also attempted to obtain legal assistance. Her confidence ratings reached the highest possible rating in Session 2, and she was able to maintain confidence and tenaciously work toward her objectives throughout the group phase.

Based on her responses to the end-of-group reflections form, explained on the previous pages, the participant appears to have enacted what she learned during the group meetings according to the concepts of empowerment, the independent living philosophy, and sense of community. In terms of the independent living philosophy, the participant reported that she became aware of the ADA and learned more about sources for free legal advice and specialized transportation options. With respect to empowerment, the participant reported feeling optimistic and empowered regarding the possibility that she may still be able to pursue the private disability income. She also felt empowered in learning activity pacing (the envelope theory) to help her manage symptoms and in knowing that she could obtain books on tape free from the library to listen to when she felt too tired to read. With respect to sense of community, the participant reported: "It's good to have a sense of community—to be able to vent what's going on with myself and my health to others who have been there and understand—and can make suggestions from experience."

The perspectives presented indicate that participants can initiate and direct their own goals and plan care effectively with peer support, despite the fact that CFS is a highly complex and difficult illness to manage. As a whole, the CFS Empowerment Project applied the methods of PAR to its design, implementation, evaluation, and dissemination. For instance, individuals with CFS highly familiar with the needs of the CFS population shaped the design and development of the research proposal and made useful suggestions regarding the structure, pacing, and resources that would be required to retain and support participants in the program. In addition, results of a national survey of service needs of people with CFS conducted by our research team (Jason et al., 1996) were incorporated into program planning and selection of topics for the peer counseling groups and one-on-one self-advocacy training period. In terms of the program, the principal investigator collaborated with Center for

Independent Living staff to employ two high-functioning individuals with CFS to serve as peer counselors. The peer counselors absorbed primary responsibility for implementing the entire program in collaboration with the participants themselves. Moreover, participants shaped the contents of the peer counseling groups during a focus group in which they selected and refined 7 of 12 potential educational topics to be presented during the group phase. Participants also assumed control of the program by setting, working toward, and evaluating their own goals. Participants also exerted an impact on the program by providing written feedback and suggestions, many of which were incorporated into the continued implementation of the project. Finally, participants have been involved in the outcome dissemination process by discussing their experiences in the program and sharing personal outcomes resulting from the project. These outcomes will eventually be used to shape the types of support provided by centers for independent living and other community-based organizations.

Conclusion

In this chapter, PAR has been described in terms of its definition, epistemology, and relevance for theory and practice in community-based research. We have suggested that there are three epistemological assumptions in PAR that involve empowerment through the generation and acquisition of knowledge, and we have provided a case example that illustrates how individuals with CFS can empower themselves through varied forms of knowledge generated by a participatory action research program. We have described a program that involved ongoing reciprocal feedback and communication between the participants, the community-based organization, and the researchers such that the program could be developed and refined in an ecologically relevant way, leading to its sustainability within the community-based organization over time. In the case study, participants assumed a moderate degree of control over the research process, high collaboration in the process, and a high degree of commitment to the process.

In sum, the program illustrated the seven general principles of PAR reviewed in this chapter. First, both the community-based organization and the community of interest—people with CFS—were active participants in the planning, implementation, and dissemination of the research. Second, the participants were successfully able to transform their own social reality by increasing their control over their own health. They also succeeded in transforming the social reality of access to community-based resources for other individuals with CFS living in the area by increasing their presence and degree of power within the community-based organization, the Center for Independent Living, such that the program could be sustained over time. Third, the problem of lack of knowledge about ways to manage CFS and a lack of knowledge about the availability of and entitlement to community-based resources that have been traditionally available to individuals with other types of disabilities was defined by individuals with CFS that planned the program and was addressed by the participants during the program, through educational presentations, self-advocacy training regarding rights and entitlements for persons with disabili-

ties, and through the exchange of information about available resources. As a result, both the participants and the community-based organization achieved a more authentic picture of the social reality of individuals with CFS as persons with disabilities willing and able to empower themselves through knowledge and by learning their rights to access the resources and services to which they are entitled. Participants in the program also engaged in an ongoing dialogue about the program and about their service needs in general, not only with the researchers but also with staff from the community-based organization. As a result, both the researchers and the community-based organization acquired new knowledge about the advocacy and service needs of individuals with CFS, and participants became more aware of what it meant to become a part of the independent living movement.

The project assumed a strengths-based approach in which participants were encouraged to recognize, use, and build on their own strengths and existing resources to accomplish their goals. Finally, the project led to personal change in both the participants and the researchers. As a result of the project, participants began to see new roles and possibilities for themselves as activists within their communities, such as within their families, social networks, and places of employment. In turn, the researchers have been influenced to replicate the program for individuals with other conditions and disabilities involving severe fatigue.

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