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SPECIAL COMMUNICATION

Developing, Testing, and Sustaining Rehabilitation Interventions Via Participatory Action Research

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Abstract

Few published intervention studies in the rehabilitation literature have included consumers in the research process other than as study participants. This lack of consumer involvement in intervention research may contribute to the challenges encountered developing, translating, disseminating, and sustaining evidence-based rehabilitation interventions in clinical practice. The overall objective of this article is to promote the integration of participatory action research (PAR) into rehabilitation intervention research as a mechanism for addressing these gaps. First, we outline essential components of a PAR model across 5 key phases of intervention research, specifically: agenda setting, methods, implementation, diffusion/dissemination, and sustainability. Second, we describe the use of PAR in rehabilitation intervention research within each of these phases by reviewing relevant literature and by providing an illustrative research example from a randomized controlled trial that integrated PAR throughout the research process. Finally, we conclude with a discussion of 5 specific recommendations for promoting the integration of PAR into rehabilitation intervention research.

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> "If research on disability is to prove useful it should help our understanding in such a way that we can provide better services, prevent and ameliorate problems, and make better programmatic and policy decisions, all for the ultimate purpose of improving the lives of those we study."[1(p308)]

Rehabilitation scholars have long pointed out the importance of not only making rehabilitation research useful to persons affected by the disability being studied,[1-4] but also of having persons with disability actively participate in setting the rehabilitation research agenda.[1,3] Over the past 50 years, increasing efforts have been made to highlight and pursue this ideal. As early as 1964, Dembo[5] described the importance of the insider-outsider distinction for understanding what the term disability might mean for those impacted by it and for informing theory, research, and practice. Since 1991, the National Institute on Disability and Rehabilitation Research has formally recognized the utility of involving consumers in disability and rehabilitation research, termed participatory action research (PAR).[6] To date, consumer participation in rehabilitation research has informed a range of topics, such as the experience of living with a disability,[7-9] program development,[10,11] factors affecting employment,[12-14] preferences for health care services[7,15] or housing,[16,17] assistive technology,[18,19] identification of health inequities,[20] and measurement development.[21,22]

The larger medical research community, including the National Institutes of Health Office of Behavioral and Social Sciences Research,[23] has also heeded a call to include consumers in research design and execution. For example, consumer involvement in health research has been advised for promoting community-based health screenings,[24] for improving public participation in medical

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research,[25] for increasing the external validity of randomized controlled trials (RCTs),[26] and for addressing health disparities for ethnically underserved minorities and lower socioeconomic status groups.[27,28] Consumer participation in medical research has also been recommended as a strategy for bridging the knowledge translation gap between science and practice.[28] Consumer participation in health intervention research is thought to facilitate the adaptation of interventions to specific clinical and community settings and cultures, thereby improving external validity.[26,28] It has also been linked with improved dissemination, uptake, and sustainability of interventions after the research funding has ended.[24,28,29]

Yet, despite the long history of acknowledging the importance of the insider perspective in disability and rehabilitation research and its application to a variety of research areas, PAR is more often the exception than the norm.[6,30] As noted by Olkin,[1] people with disabilities are underrepresented in teams designing and conducting research, resulting in a "rift between research and practice" and "a schism between those studied and those doing the studying."[1(p320)] As subsequently detailed, this gap is particularly evident when examining rehabilitation intervention research: very few published intervention studies in the rehabilitation literature have included consumers in the research process in roles other than research subject. This lack of meaningful consumer involvement may contribute to the current challenges of developing, translating, disseminating, and sustaining evidence-based rehabilitation interventions in clinical practice and community adoption.

The overall objective of this article is to promote the integration of PAR into rehabilitation intervention research as a mechanism for addressing these gaps. In service to this aim, we outline essential components of a PAR model across 5 phases of intervention research, specifically: agenda setting, design, implementation, dissemination, and sustainability. We then describe the use of PAR in rehabilitation intervention research within each of these phases by reviewing relevant literature and by providing an illustrative research example from an RCT that integrated PAR throughout the research process. Finally, we conclude with a discussion of 5 specific recommendations for promoting the integration of PAR into rehabilitation intervention research. Although other articles[6,31,32] have prescribed strategies for implementing PAR in rehabilitation research, none has reviewed the literature specific to intervention research within a rehabilitation context.

Model for using PAR in rehabilitation intervention research

Various definitions exist for the construct commonly referred to as PAR in the rehabilitation field.[6] Although the term is used in a variety of ways across fields of study, including the social sciences, public health, disability studies, anthropology, business, and education, common elements of this approach are aptly summarized in a systematic review of health-related PAR,[33] termed community-based participatory research (CBPR) by the Agency for Healthcare Research and Quality (AHRQ). The AHRQ[33] defined CBPR as "a collaborative research approach that is designed to ensure and establish structures for participation by communities affected by the issue being studied, representatives of organizations, and researchers in all aspects of the research process to improve health and well-being through taking action, including social change."[33(p3)] They stated that this approach involves: (1) "co-learning and reciprocal transfer of expertise" by researchers and consumers alike; (2) "shared decision making power"; and (3) "mutual ownership of the processes and products" resulting from the research collaboration.[33(p3)] PAR also entails "meaningful consumer involvement in all phases of the research process" and "mutual respect for the different provinces of knowledge that the team members have."[6(pS3)]

List of abbreviations:

ACA	Amputee Coalition of America
AHRQ	Agency for Healthcare Research and Quality
CBPR	community-based participatory research
JHU	Johns Hopkins University
PALS	Promoting Amputee Life Skills
PAR	participatory action research
RCT	randomized controlled trial

Building on previous definitions[6,33] and our experiences implementing PAR within an RCT of a rehabilitation intervention, we developed a model that provides a visual depiction of how PAR may be incorporated across 5 phases of an intervention study, including agenda setting, design, implementation, dissemination, and sustainability (fig 1). This model is intended as a heuristic guide and does not delineate all the possible ways that PAR can be incorporated into the research, knowledge translation, and policy processes. Although much of the focus in the PAR literature has been on involvement of people with the disability under study, we propose that PAR should also include other relevant stakeholders, including consumer advocacy groups, health care providers, payers, and policymakers.

Olkin[1] wrote that "…people with disabilities (should) be allowed a more prominent and influential role in research at every stage of the process, but most especially, in determining the questions worth asking."[1(p320)] Ideally, PAR should inform the first phase in the model, the agenda setting phase, during which decisions are made about the research priorities, aims, and questions. During the design phase of an intervention study, many decisions must be made a priori that impact the ultimate feasibility of the study and the validity and sustainability of the intervention being evaluated. For example, when designing an RCT of a behavioral therapy for chronic pain, critical choices about the specific nature of the intervention, including its components (eg, relaxation, cognitive restructuring, behavioral activation), means of delivery (eg, individual, group, in person, telehealth), and dose (eg, number and length of sessions) are necessary. Selection of inclusion/exclusion criteria, recruitment procedures, randomization procedures, and outcome measures are also decided. Inclusion of stakeholders in the decision-making that occurs during this phase hypothetically may increase the ecological validity and acceptability of the intervention and RCT to the study population. The implementation phase entails execution of the procedures, including participant enrollment, intervention delivery, and outcome assessment. Stakeholders may contribute in a variety of ways to implementation, such as advertising the study, recruiting participants, troubleshooting implementation problems, or delivering the intervention.

During the dissemination phase, investigators typically conduct analyses, interpret findings, disseminate their findings (often primarily through professional publications and scientific conferences), and plan for future research based on the findings. PAR may be used across all of these dissemination activities but also in disseminating results to other stakeholders, such as health