
SPECIAL COMMUNICATION

Participatory Action Research Designs in Applied Disability and Rehabilitation Science: Protecting Against Threats to Social Validity

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Abstract

Researchers and disability advocates have been debating consumer involvement in disability and rehabilitation science since at least 1972. Despite the length of this debate, much confusion remains. Consumer involvement may represent a spirit of democracy or even empowerment, but as a tool of science, it is necessary to understand how to judge its application. To realize consumer involvement as a design element in science, researchers need a framework for understanding how it can contribute to the scientific process. The thesis of this article is that a primary scientific function of consumer involvement is to reduce threats to the social validity of research, the extent to which those expected to use or benefit from research products judge them as useful and actually use them. Social validity has traditionally not been treated with the same rigor as concerns for internal and external validity. This article presents a framework that describes 7 threats to social validity and explains how 15 forms of consumer involvement protect against those threats. We also suggest procedures for reporting and reviewing consumer involvement in proposals and manuscripts. This framework offers tools familiar to all scientists for identifying threats to the quality of research, and for judging the effectiveness of strategies for protecting against those threats. It may also enhance the standing of consumer involvement strategies as tools for protecting research quality by organizing them in a way that allows for systematic criticism of their effectiveness and subsequent improvement. Archives of Physical Medicine and Rehabilitation 2013;94(1 Suppl 1):S20-29

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The purpose of applied research in disability and rehabilitation is to develop empirically derived solutions to problems experienced by people with disabilities.¹⁻³ Researchers apply a wide range of scientific methods to develop solutions that may include mechanical and electrical technologies, medical and pharmacologic treatments, and behavioral and social technologies (including laws, policies, programs, and treatment techniques). To be considered truly successful, findings from the research must actually be used.

Over the past 30 years, researchers and advocates have debated the role of people with disabilities in the conduct of disability and rehabilitation science.⁴⁻¹¹ This debate has tended to focus on the concepts of participatory action research (PAR).^{12,13} The broader

fields of medicine and health focus on concepts of patient-centered outcomes research and community-based participatory research.¹⁴ While these discussions have been useful, researchers need a structured framework to realize consumer involvement as a design element in science.¹⁵

The thesis of this article is that a primary scientific function of consumer involvement is to reduce threats to the social validity of research, the extent to which potential adopters of research products judge them as useful and actually use them. This article briefly reviews the history of consumer involvement in disability and rehabilitation research, introduces and defines the concept of social validity, compares social validity with internal and external validity, and describes threats to social validity. Importantly, it presents a framework for judging the extent to which different forms of consumer involvement protect against threats to the social validity of research. It also reviews several forms of consumer involvement as a means of explicating the scientific function of consumer involvement.

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History of consumer involvement

The idea of involving end users in research is neither new nor unique to disability and rehabilitation science. The agricultural research and extension service has long involved a partnership among farmers, ranchers, agricultural workers, field agents, and researchers. Rogers and Shoemaker¹⁶ report on the lessons learned by agricultural researchers in the 1920s when they did not involve farmers in the development and dissemination of hybrid seed corn. Early on, it was tested in the Southwestern United States. Despite the increased yield in corn, farmers quickly rejected it. It seems that the corn meal produced from processing the corn was not suitable for making tortillas. Research and development had indeed produced a more efficient variety of corn, but it produced flour that had limited value to intended consumers. From this and similar experiences, agricultural researchers began to consider consumer concerns in research, development, and dissemination.

A recognized parallel in disability and rehabilitation science is the abandonment of assistive technology by people with disabilities.¹⁷⁻²¹ There are numerous reports of elegant assistive devices that had been demonstrated as effective and reliable by engineers, but which were discarded because they did not meet consumers' needs. This has led rehabilitation engineers to call for the involvement of consumers in the development of assistive technologies.²² The involvement of consumers in disability and rehabilitation research began at least by the early 1970s.²³ For example, Remmes²⁴ presented a paper at the 1972 meeting of the National Association of Rehabilitation Research and Training Centers in which he stated that people with disabilities want to participate in any decision-making process that affects their lives, and suggested that consumers could become a positive force in rehabilitation research.

In the late 1970s, the emergence of the independent living movement, with its roots in civil rights and consumerism, asserted that people with disabilities should control all aspects of their lives, from medical care to employment choices.^{25,26} By extension, this included controlling research that used resources targeted at issues of importance to them.

The literature on consumer involvement in disability and rehabilitation science has grown steadily since then.²⁷ A particularly important contribution to the debate was the identification of PAR as a means of conveying a spirit of such involvement and possible methods for achieving it.²⁸ Still, confusion remains about the nature and purpose of PAR; some argue that it is a philosophy, others that it is a method, and still others that it is a grab-bag of procedures, and, of course, some argue for its use and others against it. Given the importance of consumer involvement to the funding and practice of disability and rehabilitation science, efforts to clarify its purpose and characteristics are warranted.²⁹

Social validity

Wolf³⁰ defined social validity as the extent to which potential adopters of research results and products judge them as useful and actually use them. Social validity involves judgments of the importance of research goals, the acceptability of procedures, and

the significance of impact by those expected to use its results or to benefit from them. Wolf³⁰ argued that when behavioral researchers attend to the social validity of their research, the probability that their research would be supported by the public or be used to solve problems increases.

Threats to social validity

A primary concern in the scientific study of behavioral and social phenomenon, as well as medicine and engineering, has been the internal and external validity of the research results.³¹ To incorporate consumer involvement as a design element in science, researchers need tools for assessing threats to social validity and assessing the effectiveness of strategies for protecting against those threats. Such tools are needed by those who review research proposals in the design stage (eg, human subject protection committees), by those who formally review proposals to make funding recommendations, and by journal editors and peer reviewers when reviewing research reports for publication. They are also useful for policy-makers, program managers, and professional service providers who are considering the implementation of a finding, and for consumers judging whether to adopt a new approach.

Framework for assessing protection against threats to social validity

Campbell and Stanley's³² classic description of and rules for judging internal and external validity of experimental and quasi-experimental research designs provides a framework for organizing and evaluating social validity. Table 1 lists 15 commonly used consumer involvement procedures and assesses the degree to which they can help protect research against 7 distinct threats to social validity. First, several threats to social validity are explained with selected examples of how consumer involvement helps protect against the threat. Next, several forms of consumer involvement are described and their method of protection explained.

Threats to the social validity of applied research

As with threats posed to internal and external validity of research designs, there are numerous threats that challenge the social validity of applied research. These include threats posed by: (1) selecting irrelevant topics for research, (2) a lack of clarity about important consumer goals, (3) misunderstanding the acceptability of research methods, (4) misunderstanding the range of intervention acceptability, (5) ignoring criteria that potential adopters would use to judge the significance of outcomes and impacts, (6) misinterpreting results, and (7) lacking generality of findings in real-life application. Table 1 lists these threats and summarizes the degree to which different forms of consumer involvement may help protect against those threats. The following sections describe the column headings for table 1.

Threats posed by selecting irrelevant issues

The first threat to social validity involves selecting an issue or problem for research that lacks importance or relevance to a constituency. Many researchers are interested primarily in theoretic, methodologic, or measurement issues. For research with such a focus, the actual content of study may be arbitrary except to the extent that it provides a heuristic mechanism for developing or

List of abbreviations:

CEI Community Engagement Initiative
CIL center for independent living
PAR participatory action research

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