

Brief Report

A community-based participatory research approach to the development of a Peer Navigator health promotion intervention for people with spinal cord injury

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Abstract

Background: Recent trends indicate research targeting outcomes of importance to people with disabilities, such as spinal cord injury (SCI), may be best informed by those individuals; however, there are very few published rehabilitation intervention studies that include people with disabilities in the research process in a role beyond study participant.

Objective: To describe a community-based participatory research (CBPR) approach to the development and pilot testing of an intervention using community-based Peer Navigators with SCI to provide health education to individuals with SCI, with the goal of reducing preventable secondary conditions and rehospitalizations, and improving community participation.

Methods: A CBPR framework guides the research partnership between academic researchers and a community-based team of individuals who either have SCI or provide SCI-related services. Using this framework, the processes of our research partnership supporting the current study are described including: partnership formation, problem identification, intervention development, and pilot testing of the intervention. Challenges associated with CBPR are identified.

Results: Using CBPR, the SCI Peer Navigator intervention addresses the partnership's priority issues identified in the formative studies. Utilization of the framework and integration of CBPR principles into all phases of research have promoted sustainability of the partnership. Recognition of and proactive planning for challenges that are commonly encountered in CBPR, such as sharing power and limited resources, has helped sustain our partnership.

Conclusions: The CBPR framework provides a guide for inclusion of individuals with SCI as research partners in the development, implementation, and evaluation of interventions intended to improve outcomes after SCI. © 2014 Elsevier Inc. All rights reserved.

Keywords: Spinal cord injury; Community-based participatory research; Intervention; Navigation; Secondary conditions

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CBPR in disability and rehabilitation research

A recent review of the rehabilitation literature revealed there are very few published rehabilitation intervention studies that include people with disabilities in research in a role beyond study participant.¹ Research implemented with the goal of improving the lives of persons with disabilities, such as spinal cord injury (SCI), must reflect the demands of living in their environment of choice and engaging in activities that are of importance to them.² The disability community has expressed a need for inclusive, action-based research methodologies in which people with disabilities function as partners and consultants, not as research subjects.³ Disability scholars emphasize that research involving people with disabilities should embrace respect for human rights, and work toward the advancement of social justice for people with disabilities.⁴

Developing a program of disability research that does not marginalize people with disabilities but promotes empowerment and autonomy can be challenging, especially for the able-bodied researcher. A community-based participatory research (CBPR) approach engages community members as decision-making partners in the research process and provides a means to elicit community concerns and priorities that otherwise might not enter into the researchers' agenda.^{5,6} Additionally, community members can advise about suitable research processes that are respectful of and acceptable to the community. Ideally, CBPR processes promote shared ownership of research projects between academic investigators and

participants, provide for community-based analysis of social problems, and support interventions that involve community action.⁷ The fundamental principles of CBPR position the community as an equal partner in all phases of research, from defining the research question to knowledge dissemination.⁸ The processes of CBPR build upon the community's strengths, ensure local relevance, and promote capacity building and, more specifically, engage people with disabilities, such as SCI, as partners in research.^{8,9} Additionally, participatory approaches to disability and rehabilitation research hold the potential to temper threats to the social validity of research, defined as the "extent to which potential adopters of research products judge them as useful and actually use them" (p. S20).¹⁰

Although CBPR has many advantages, there are also associated challenges. Barriers created by academic institutional practices, such as research ethics boards and university reimbursement processes are commonly cited.^{11,12} CBPR requires increased time and resources to facilitate partnerships, including establishing a trusting relationship and providing training.^{13,14} Building and maintaining the equitable partnerships required for CBPR is a complex process that requires consistent attention to power, accountability, and ownership of the products of research within the partnership.^{11–14}

In this paper we describe a CBPR framework (Fig. 1) to inform intervention research.¹⁵ Our current study investigates using community-based Peer Navigators with SCI

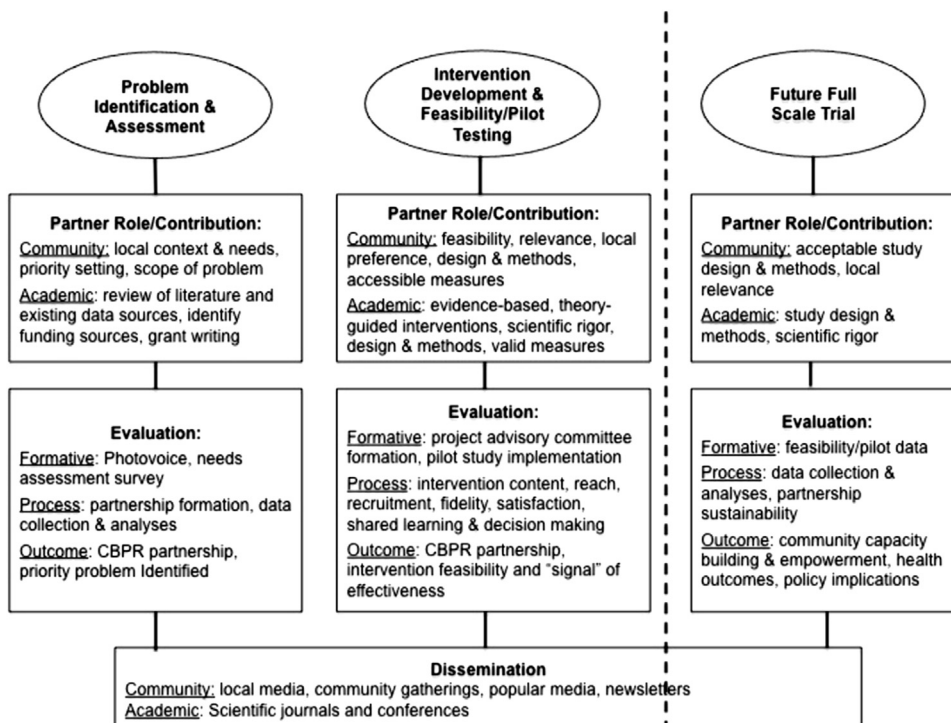


Fig. 1. CBPR framework to guide intervention research.

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