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# Developing a Community Based Rehabilitation Network for People with Spinal Cord Injury: A Case Study in Appalachian Kentucky

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## Abstract

This case study describes the process of developing a community based, collaborative network in underserved Appalachian Kentucky, focused on the needs of people with spinal cord injury. The goal of the project was to develop a network to disseminate information and maximize resources to improve quality of life and health outcomes for individuals with spinal cord injury (SCI) living in rural Appalachian Kentucky. The counties located in eastern Kentucky are some of the poorest in Appalachia and have significant shortages of healthcare resources. A community-academic partnership was developed to guide the creation of a network of stakeholders in rural communities who are impacted by SCI. Initial interviews and focus groups guided the creation of the network and the topics of importance to the people/families living with SCI and the healthcare providers in this rural region. Conclusions from the case study highlight the supports and barriers to the creation of the community based network. While many individuals, businesses and healthcare providers quickly joined the network development process, similar barriers that influence health disparities in rural underserved populations were faced in developing this network. Geographic isolation and transportation issues negatively impacted full participation in the network. However, many participants are thriving in this collaboration. This case study shows how a community based network of people working together can translate research results into a meaningful foundation to develop programs that will positively influence health and quality of life outcomes for underserved populations in underserved regions.

Keywords: rural health, rehabilitation, community-based participatory research, spinal cord injury, underserved populations, Appalachia

## 1.0 Introduction

Of the 420 counties that comprise Appalachia, the counties located in eastern Kentucky are some of the poorest. Approximately 80% of these Kentucky counties have shortages of Health professionals and healthcare resources. This shortage is a particular burden to individuals with neurological impairment who require a collaborative inter-professional approach in order to achieve long-term improvement in health outcomes and quality of life. This case study will describe the development of The Kentucky Appalachian Rural Rehabilitation Network (KARRN). KARRN has been established as a collaborative team including individuals impacted by spinal cord injury (SCI), providers who serve them, members of communities in which they live, advocates, educators, and researchers who investigate this impairment. The goal is to identify, develop and disseminate information and strategies, and maximize resources to improve outcomes and quality of life for individuals with SCI living in rural Kentucky Appalachian counties.

## 2.0 Background

Spinal cord injury (SCI) often results in permanent loss of motor and sensory function that significantly impacts the person's quality of life. Secondary complications following SCI (e.g. spasticity, urinary tract infections, pressure sores, and osteoporosis) significantly impact the individual's quality of life by limiting functional abilities and participation in desired roles and activities. Rehabilitation providers have noted that people with disabilities in rural areas are at greater risk of developing secondary complications (Cardenas, Hoffman, Kirshblum, & McKinley, 2004; Chiodo et al., 2007; Noreau, Proulx, Gagnon, Drolet, & Laramee, 2000; Vogel, Krajci, & Anderson, 2002).This increased risk of secondary complications significantly impacts the individual's quality of life and ability to re-integrate into their community.

Community re-integration after hospitalization has emerged as an important goal of rehabilitation, given the current emphasis on cost containment of inpatient care and the need to decrease the length of stay (Forchheimer & Tate, 2004). People with SCI have a variety of individualized post-hospitalization needs and a specialized multidisciplinary team is required to address the diversity of needs of this population. Cox, Amsters, and Pershouse (2001) demonstrated that the greatest service barrier for SCI populations was the limited local specialist knowledge about SCI. Rural communities present special needs and barriers that differ from urban communities. Higher rates of unemployment and decreased access to rehabilitation services, for example, affect service delivery in rural communities (Lustig, Weems, & Strauser, 2004). The continued healthcare disparity in rural communities in general and specifically in Appalachia, underscores the fact that the current models of healthcare provision and resource allocation are inadequate. There is compelling need for research aimed at developing more creative models for examining long-term healthcare outcomes for individuals in rural communities.

Much of the discussion regarding translational research within the scientific community has focused on "bench to bedside" translation or, how can researchers and physicians more rapidly and efficiently transfer basic scientific discoveries into clinical applications? Less discussed, but just as important to the nation's health, is the translation of effective clinical and health promotion interventions to reach populations at risk. The knowledge gained through health disparities research is particularly appropriate to this type of "bedside to community" translational research.

Community-based participatory research (CBPR) is a collaborative process of research involving researchers and community representatives; it engages community members, employs local knowledge in the understanding of health problems and the design of interventions, and invests community members in the processes and products of research. Through community-based research, local community knowledge increases our understanding of the complex interactions among economic, social, and behavioral factors that contribute to disparities and, therefore, should inform the design of interventions aimed at reducing these disparities (Flicker, Savan, Kolenda, & Mildenberger, 2008). In addition, community members are invested in the dissemination and use of research findings and ultimately in the reduction of health disparities.

Community-Based Research (CBR) is rapidly gaining recognitions as an important tool in addressing complex environmental, health and social problems (Forcheimer et al., 2004; Frey-Rindova, de Bruin, Stussi, Dambacher, & Dietz, 2000; Giangregorio & McCartney, 2006). CBR is not a method, but an approach to research (Vogel et al., 2002), that emphasizes the importance of collaboration, participation and social justice agendas over positivist notions of objectivity and the idea that science is apolitical (Hall, 1993).

## 3.0 Research Methodology

The development of KARRN occurred in two distinct phases. Phase 1 was a funded qualitative study exploring the experience of people in rural communities who either had a SCI or worked with people with SCI. Out of that research project Phase 2 emerged. It was clear that there was a need for a network of people invested in the quality of life and health outcomes of people with SCI in rural communities. The process of developing this network is described below. This study was approved by the University of Kentucky and Cardinal Hill Rehabilitation Hospital Institution Review Boards. Funding for this project was provided through a grant by the Experimental Program to Stimulate Competitive Research (EPSCoR; funded through the National Science Foundation), which provided the funding for both Phase 1 and Phase 2 of this project.

### *Phase 1: Rural Spinal Cord Injury Research Project*

The initial research project was designed to examine the supports and barriers of individuals with SCI and their families living in rural Appalachian communities, as well as the supports and barriers of the health care professionals practicing in those rural communities.

We used a strategy adapted from the Participatory Rural Appraisal (PRA) strategy described by Kuipers, Kendall, and Hancock (2001, 2003). PRA is a research and development approach for shared learning between local people and outsiders and is based upon the World Health Organization’s model of Community-Based Rehabilitation. Using qualitative methods, volunteers and key informants were recruited to participate in the study. In-depth interviews took place and a discussion of the long-term goal of creating an on-going community-based group interested in issues related to rehabilitation in rural Appalachian Kentucky ensued. Participants were recruited through a regional rehabilitation hospital that serves a large population of people from Appalachia with SCI. Additional recruitment came through word of mouth snowball sampling. Healthcare providers were recruited by invitation if they had large practices in the region and through the participants with SCI who suggested contacts. The study was described to each participant and informed consent was collected before any information was gathered. A total of 11 in-depth interviews and 5 focus groups were conducted, with a total of 52 people participating. The interviews and focus groups helped establish a base level of knowledge regarding the specialized needs of individuals with SCI in these rural communities as well as served as a community needs assessment.

All of the interviews were tape recorded. As tape-recorded interviews were completed and transcribed, analysis took place concurrently, allowing for information learned in one interview to inform subsequent interviews. This technique allowed for an increasingly focused inquiry and increasing depth of questioning as each interview was completed. Inductive thematic content analysis was employed (Gubrium, 1993; Rubinstein, 1988; 2002; Shawler, Rowles, & High, 2001). Coding and interpretation was an ongoing iterative process. Each transcript was read several times and line-by-line color coded based on specific content categories. Hand coding of transcripts facilitated more sensitive and nuanced understanding of meanings in the narrative text (Morse & Field, 1996). Instances pertaining to each category were incorporated into separate topical files and then aggregated into more general emergent themes.

## 4.0 Initial Community Findings

The data collected during the first phase was compiled and used to develop a descriptive picture of the person's and community's experience with disability services, current realties, local conditions, and overriding constraints related to the management of SCI in rural communities. Following data analysis several themes emerged. As this was an introductory descriptive study, we were not surprised that our results merely echoed the current knowledge of health care issues in rural America as a whole. Rehabilitation patients, their families and their community providers face the well known problems of distance to services, limited services, limited access to specialists, transportation problems, depression and geographic barriers due to infrastructure and terrain (hilly, and wooded). These are commonly known problems for rural community members and one of the reasons for health disparities among this underserved population. However, there was one thing that did emerge as specific to people with SCI. They described a lack of connection and advocacy among themselves and those who work with them. There was a sense of isolation and a lack of centralized knowledge and help.

This recurrent theme of isolation and lack of support led to the second phase of this study: Establish a community-based, multifaceted collaborative team that would identify, develop, and disseminate information and strategies to improve outcomes and quality of life of individuals with SCI living in medically underserved rural communities. The information shared by the community members steered the direction of the project and the qualitative component provided the context for the decision to move on to Phase 2 of the study: network development.

## 5.0 Implementation of Community Findings

### *Phase 2: Developing the Kentucky Appalachian Rural Rehabilitation Network*

After the data was collected and analyzed in Phase 1, the people who participated in the initial study, as well as other key persons, were invited to meet and discuss the outcomes of the interviews and to discuss future steps. At the initial community meeting, held in the Appalachian, Kentucky region, a group of over 25 people formally met. The first meeting consisted of introductions, a description of the findings from the interviews, a presentation by Cheryl Vines, the Director of the Arkansas Spinal Cord Commission, and an asset mapping session.

In the rural context, assets are popularly recognized attributes of communities. They are considered essential for the maintenance of rural life and vital for the sustainability of the economy, society and environment. Asset mapping is a positive approach to learning about a community. During the asset mapping process three types of information were collected: 1) an inventory of all the good aspects about the community, 2) a ranking of the most valued aspects of the community, 3) the reasons why people place high value on assets in the community. Once this map of the valued aspects of the community is developed, you can collectively strategize about how to build on the assets in order to utilize, sustain and enhance them. Asset mapping allows for the engagement of people in the shaping of their community. This coming together around common assets changes the way communities are thought of, because it unites people around a positive identity and a collective cause (Fuller, Guy, & Pletsch, 2002).

In these times of increased economic uncertainty, it has become more imperative that the surprisingly extensive amount of community-based assets/resources be effectively utilized. In addition to the community asset mapping, a network name was created, Kentucky Appalachian Rural Rehabilitation Network, and a formalized shared mission for the network was developed:

> “A collaborative team including individuals with neurological conditions (SCI, stroke, TBI, etc), providers who serve them, members of communities in which they live, advocates, and researchers who investigate these conditions will identify, develop and share information and strategies, and maximize resources to improve outcomes and quality of life.”

Finally, during the meeting short term and long term goals were developed.

Goal Development:

<u>Short Term</u>

- Develop mentor programs/network (individual/family and providers)
- Begin developing a KARRN website
- Identify other potential KARRN members
- Analyze data describing the impact of SCI on Eastern Kentucky.

<u>Long Term</u>

- Research funding to implement and look at outcomes
- Easier, cost-effective access to medical supplies (identify supplies needed, educate local distributors)
- More accessibility within the healthcare organizations

After the first KARRN meeting, minutes were circulated to all members. An online survey was developed and conducted to gather information about the network members’ areas of interest and level of interest in future meetings. From that survey we discovered that 40% of the people at the initial meeting wanted to be core members and actively work on developing the network. An additional 50% were interested in being associate network members who would like to be kept informed and who may participate in certain events/projects. The remaining individuals wanted to be community partners who advocated for the network in their communities. Support for this initial meeting was provided through the EPSCoR grant as well as from each of the KARRN community partners providing their representatives the necessary time to attend this initial, as well as follow-up, meeting.

### *5.1 Next Steps – On Going Network Development*

The KARRN members have since met five times to continue with the network development and working on the short term goals. The first short term goal being tackled is the KARRN website. This project is currently underway and the KARRN members have met to evaluate a first and second prototype. The website contains community information, educational information, announcements of ongoing activities and has a link to existing SCI chat rooms.

A second component to the community-academic partnership is for the university partners to support ongoing education for the community members. As a thanks to the community members who volunteered their time and energy to the initial research project and the developing KARRN, a secondary outcome was the development of an educational conference related to SCI that took place in their region. This provided a way to help increase specialized knowledge to both the individuals and their families living with SCI, students in health related programs, the healthcare providers who work in these communities and other community partners. The objectives of the conference were:

1. Provide healthcare decision makers up to date, evidence-based research about prevention and treatment options to allow for the best functional outcomes and quality of life possible for people with SCI living in rural communities.
2. Provide current evidence from research to help patients and their families become better informed healthcare consumers and allow them to become more active partners in their own care.
3. Establish clinical-community relationships that are essential for the future development and dissemination of innovative and effective clinical outcomes for improving the long-term healthcare of the patients in rural communities.

Experts in the field came together from across the country to address important issues related to quality of life and community reintegration for people with SCI. Sessions were devoted to topics such as the importance of exercise and nutrition following SCI, long-term healthcare issues, medical management of SCI induced secondary complications, and developing a peer-mentor support system. The conference was specifically geared to both people with SCI and healthcare providers who work with them. By addressing both groups simultaneously, we believed it would help to develop a common language that will be essential for the continued development and growth of the network as well as its effectiveness to influence the healthcare in Appalachian Kentucky. This initial conference was supported thorough multiple organizations as well as by community partners of KARRN. These supporters included: the Kentucky Spinal Cord and Head Injury Research Trust, the University of Kentucky Spinal Cord and Brain Injury Research Center, Cardinal Hill Rehabilitation Hospital, the Eastern Kentucky University Occupational Therapy Program, the University of Kentucky Healthcare System, and by a grant provided through the University of Kentucky Vice President for Research

(Principle Investigator: Kitzman). The broad support by the community and academic partners demonstrated a common support for this community-based initiative.

## *5.2 Supports and Barriers to Developing the Network*

Developing a rural spinal cord injury network necessitated multiple partners from multiple locations. The difficulty with transportation means that any supports that are developed need to be by county not region. Rural Appalachian Kentucky is not homogenous. The counties supports and barriers differ as do the needs of the people in the counties. It is a large region with hilly, difficult terrain and not all locations are easily accessible even within a county.

The very reason the network is important and needed impacted the development of the network. Finding appropriate meeting sites that were convenient and able to provide the accessibility required for the network meetings was difficult. One facility soon became the favorite meeting place in terms of practical needs, but it meant that certain network members were less able to attend meetings and functions. Planning meetings requires the ability to keep everyone connected, particularly members from remote areas. A future goal is that the website will be one place that provides information specific to each county represented. Over and over it was suggested that the network develop a guide to community services for people with SCI in Appalachian KY.

In terms of supports for the network, it was beneficial that some close connections already existed among the network members. For example, the university and the regional rehabilitation hospital are closely connected through clinician education, research and through the university Physical Medicine & Rehabilitation physicians being housed at the free standing rehabilitation hospital. A second connection was between the Physical Therapy department at the university and the affiliate regional healthcare center in Appalachian Kentucky. There already existed a physical therapy distance learning and internship program between the two facilities. Finally the regional physical rehabilitation hospital, located in Lexington, Kentucky, is the primary acute rehabilitation care facility for Appalachian Kentucky. So the network of former clients who are now back in their communities allowed us direct access to the people and families affected by SCI. Using these preexisting connections to build on was invaluable.

Another support to developing this network was the fact that KARRN is related to physical rehabilitation. Physical rehabilitation is by necessity multidisciplinary and provides client centered care. These fundamentals were beneficial when it came to finding, connecting and supporting a vast array of people in the network. There was a certain skill level that already existed in terms of communicating with and understanding people from a variety of backgrounds with a variety of skills. Perhaps unlike other medical fields the voice of the client is crucial in physical rehabilitation. This mindset made it very easy for us to start at the beginning, the people with the SCI. This may seem obvious but in the process of developing the network we were given advice from many different groups of people, yet many of these groups did not fully understand the principles of community-based participatory research or community-academic partnerships. This was particularly true of other medically based groups interested in rural health.

### *5.3 Sustainability*

It was recognized early on that for long-term sustainability to occur, each of the community partners needed to pledge continued support for this developing organization. Each of the partners has in fact made this pledge and continues to support their representatives in attending meetings. In addition, KARRN continues to add new members to its organization. Through the addition of community-based groups, long-term sustainability has become more feasible since the KARRN as a whole does not rely solely on any one entity for it growth and survival. Funding for the development of KARRN as well as its educational and support programs continues to be sought through grant applications, and several members of KARRN have recently been successful in obtaining funding through organizations such as the Paralyzed Veterans of America, the Christopher and Dana Reeve Paralysis Foundation as well as the National Institutes of Health/ National Center on Minority Health and Health Disparities.

## 6.0 Summary

It became clear during the process of developing KARRN that this was an important and welcomed idea in the rural Appalachian community. The sense of having a say, being listened to and building connections with others in their community helped lessen the feeling of isolation and neglect for both people with SCI and those who lived and work with them. For underserved populations this style of collaboration is beneficial to all involved. The researcher is allowed greater access to the lived reality of the community and the community is allowed greater access to potential services and support. The collaborative and iterative process of participating in community collaboration resulted in the continuously developing connections and multiple agreed upon goals and projects. The future plan is to broaden the KARRN to include other diagnosis/disabilities such as brain injury and stroke among rural Appalachian communities.

## 7.0 Acknowledgments

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