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Evolution of a Community-Based Participatory Approach in a Rural and Remote Dementia Care Research Program

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Abstract

Background: Community-based participatory research (CBPR) approaches are valuable strategies for addressing complex health and social problems and powerful tools to support effective transformation of social and health policy to better meet the needs of diverse stakeholders.

Objectives: Since 1997, our team has utilized CBPR approaches to improve health service delivery for persons with dementia and their caregivers in rural and remote settings. We describe the evolution of our approach, including benefits, challenges, and lessons learned over the last 15 years.

Methods: A multistage approach initiated an ongoing CBPR research program in rural dementia care and shaped its direction based on stakeholders' recommendation to prioritize both community and facility-based care. Strategies to develop and foster collaborative partnerships have included travel to rural and remote regions, province-wide community meetings, stakeholder workshops, creation of a Decision-Maker Advisory Council to provide ongoing direction to the overall program, development of diverse project-specific advisory groups, and a highly successful and much anticipated annual knowledge exchange and team-building event.

Lessons Learned: Partnering with stakeholders in the full research process has enhanced the research quality, relevance, application, and sustainability. These benefits have supported the team's evolution from a relatively traditional focus to an integrated approach guiding all aspects of our research.

Conclusions: Developing and sustaining the full range of stakeholder and decision-maker partnerships is resource- and time-intensive, but our experience shows that community-based participatory strategies are highly suited to health services research that is designed to support sustainable service delivery improvements.

Keywords

Community-based participatory research, integrated knowledge exchange, collaborative research, rural, dementia

Partnerships between academic and community organization aimed at addressing complex health problems have become widely adopted over the past two decades.[1] Such CBPR approaches, also known as community-involved research, community-centered research, community-based action research, and community participatory action research, emphasize the participation and influence of nonacademic partners in the process of creating and applying knowledge.[2,3] A systematic review commissioned by the Agency for Healthcare Research and Quality defined CBPR as a collaborative research approach "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."[4(p.3)] It includes elements of "integrated knowledge translation," participatory, action-oriented research focusing on knowledge users' problems.[5,6]

CBPR is rooted in several traditions, including the action research approach of Kurt Lewin,[7] and the participatory and emancipatory approaches emerging from feminist, post-modern, and postcolonial research.[8] These relational, process-oriented paradigms have evolved as post-positivist alternatives to traditional research approaches that test a priori hypotheses and emphasize separation between researchers and knowledge users.[3] Such approaches recognize that addressing complex questions embedded in social structures requires an equalization of power between researchers and communities.[3] The advantages of CBPR are that it improves the relevance, quality, validity, usefulness, and application of the research[2]; enhances the sustainability of interventions[3]; joins partners with diverse skills and knowledge in addressing complex problems; helps to overcome the distrust by communities that have historically been subjects of research; and provides resources for communities.[9]

The extent to which a particular research endeavor achieves the core principles of CBPR[2,9] varies depending on the context, purpose, and participants.[2] Guidelines for assessing participatory research projects were developed in 1995[10] and revised in 2008.[11] Key differences were replacement of "community" with the more inclusive "nonacademic partners" and "intended users," explicit use of the terms "capacity building" and "sustainability," and the consideration of benefits for both nonacademic partners and researchers.[11] In this paper we use the terms community partners, stakeholders, and decision makers interchangeably.

Because of the active participation of community partners in decision making and their ownership of outcomes, CBPR has been described as a promising strategy among hard-to-reach and poorly understood populations.[12] A report on the health of rural Canadians[13] identified that complex relationships between health and place are not well understood. The Canadian Institutes of Health Research (CIHR) has identified reduction of health inequalities in vulnerable populations, including rural and remote communities, as a priority.[14] Their Strategic Plan emphasizes solutions-based research involving researcher–knowledge user collaboration to increase research uptake.

Since 1997, members of our research team and community partners have developed a CBPR program aimed at improving health service delivery for persons with dementia and their caregivers in rural and remote settings. Over time, new researchers have joined the team; our partnerships with decision makers have become more collaborative as we recognized the mutual benefits of this approach. This paper describes the evolution of our research team's CBPR program over the last 15 years. Using current theoretical perspectives on CBPR we assess the benefits, challenges, and lessons learned. More information is available at http://www.cchsa-ccssma.usask.ca/ruraldementiacare/. All of the research projects reported herein received approval from the Behavioral Research Ethics Board of the University of Saskatchewan and had the consent of participants.

RURAL DEMENTIA CARE FOCUS

Recent reports have highlighted the growing global prevalence and incidence of dementia and the urgent need for strategies to improve the care and support of individuals with dementia and their caregivers.[15,16] The 2012 report from the World Health Organization entitled, *Dementia: A Public Health Priority*, estimated a worldwide prevalence of 35.6 million, which is projected to double every 20 years. The total estimated worldwide cost of dementia is US$604 billion.[15] The report *Rising Tide: The Impact of Dementia on Canadian Society*[17] forecasts a doubling of dementia prevalence in Canada by 2038. Rural areas will be disproportionately affected because of the higher proportion of older adults.[18] Systematic reviews of informal dementia care[19] and formal services for dementia[20] in rural and remote areas identified rural-specific barriers, such as time, travel, cost, and lack of access to services and educational opportunities.

The research program reported herein was conducted in the western Canadian Prairie province of Saskatchewan (population, 1,072,082; area, 651,035 km^2; population/km^2, 1.88).[21] In 2011, 39.1% of the population was classified as rural and small town (population less than 10,000).[22] Recent Saskatchewan census data show a higher proportion of seniors over age 65 living in towns (21.3%), villages (20.1%), and recreational villages (25.8%), compared with cities (14.0%).[22] Initially, the researchers involved in the program were all based at the University of Saskatchewan, in the city of

Saskatoon (population 236,000), although several have since relocated within Canada.

LAUNCHING A PROGRAM OF RURAL DEMENTIA CARE RESEARCH

Several members of the research team first began working together in 1990. In 1997, as first-time community-based researchers, we were guided by the 1995 guidelines for participatory research developed by Green et al.[10] A multistage approach was used to initiate an on-going research program in rural dementia care. We traveled to all 30 health districts in Saskatchewan (now 13 regions) to meet with their community-based boards, establish collaborative relationships, and assess research needs. Based on the strong support for rural-based evidence in dementia care, we held a 1-day workshop with representatives of 27 districts to identify research priorities and design an initial study. A clear message emerging from the meetings and workshop was that the program should include community-based and long-term care, to address challenges across the care continuum. A report of the workshop outcomes was distributed to all participants and health districts. Finally, we conducted a comprehensive pilot study of our initial research design in one district. The study identified challenges in providing dementia care in the community[23] and in small rural nursing homes,[24,25] and led to a follow-up study comparing rural facilities with and without dementia special care units.[26-28] The early involvement of decision mak-

ers has profoundly shaped the research program. A weakness of our early approach, however, was the limited collaboration with decision makers beyond the development of the study questions and design.

A NEW EMERGING TEAM

In 2003, our team expanded in response to a call from CIHR for the New Emerging Team (NET) program, designed to provide 5 years of support for interdisciplinary research teams. Our program's conceptual model, *Strategies to Improve the Care of Persons with Dementia in Rural and Remote Areas* (Figure 1), included three core studies that crossed the care continuum. The program also included a number of related projects, some of which were outlined in the proposal and others that emerged later during engagement with communities and service providers. The program was aimed at improving health care delivery, including the availability, accessibility, and acceptability of services for rural and remote people with dementia, including Aboriginal seniors.

The NET "flagship" study (Study #1) involved the development and evaluation of a 1-day, one-stop interdisciplinary Rural and Remote Memory Clinic (RRMC) for early assessment and diagnosis, which included telehealth videoconferencing for pre-clinic assessment and follow-up appointments to reduce repeated travel over long distances. Study #2 (analysis of Statistics Canada's Community Health
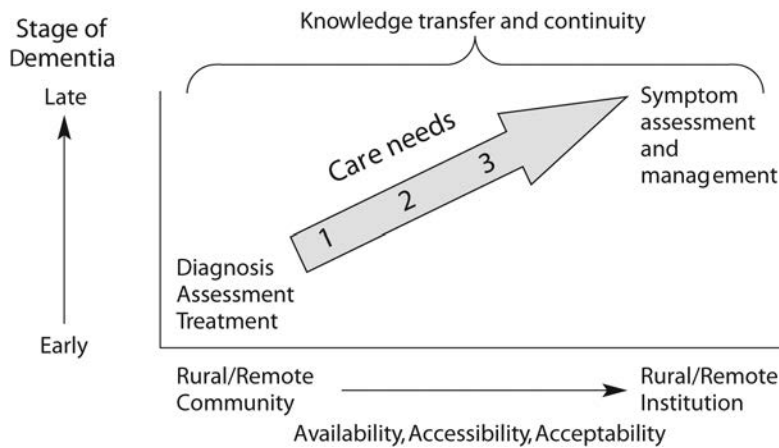

Figure 1. Conceptual Model for Research Program "Strategies to Improve the Care of Persons With Dementia in Rural and Remote Areas"

Note: Originally published in Morgan et al., 2005[32].

Survey database[29]) and Study #3 (evaluation of the Alzheimer Society's Enhancing Care Program[30]) were conducted using more traditional approaches because of the type of data (#2) and the timelines imposed by a student project (#3). More information about the NET program and the RRMC is available elsewhere.[31-34] The RRMC study and several related projects followed a CBPR approach, a sample of which are described in more detail herein. "Community" is defined differently in each project.

The RRMC Study

Although CIHR did not require decision-maker involvement in these grants, NET researchers believed that a CBPR approach was critical to ensuring relevance of the research and building of capacity to improve dementia care. During proposal planning, a broad range of stakeholders helped to develop the RRMC study, including healthcare providers, rural and remote telehealth coordinators, and Telehealth Saskatchewan. Once funded, the first year was focused on partnership and program development with a wide range of intended users. Meetings were held with local healthcare providers in the 14 rural and remote communities supported by the Telehealth network, with researchers traveling close to 7,000 km. These meetings were aimed at building relationships, planning the clinic's format, and designing the program evaluation. We subsequently conducted a survey of participants' comfort and confidence in providing dementia care and their continuing education needs, which has informed ongoing program development.[35] The development process also helped to identify key partners for individual NET projects. All RRMC patients and families are invited to partner in our research through their evaluation of clinic processes, with feedback used for continuous quality improvement.

Development of Culturally Appropriate Cognitive Assessment Measures

Aboriginal seniors are a rapidly growing segment of the population in Saskatchewan and Canada.[36] Earlier research identified the importance of incorporating cultural values in dementia assessment and treatment protocols.[37,38] As a first step, researchers partnered with members of an Aboriginal Grandmothers group with experience in providing care to Aboriginal seniors. The group's coordinator at the community clinic attended some meetings and traveled with the researchers on northern visits. This study was aimed at improving understandings of cultural perceptions of normal aging and dementia in an Aboriginal population and guiding development of culturally appropriate assessment techniques and tools. Six 3-hour sessions were held over 6 months. To ensure their voice was represented, the Grandmothers reviewed all transcripts and participated in an iterative process of thematic analysis.[39]

Based on the Grandmothers' recommendations, existing screening instruments and neuropsychological testing protocols were modified to increase their cultural appropriateness for Cree-speaking Aboriginal older adults[39,40] and a new screening tool, the Northern Cultural Assessment of Memory, was developed for use by front-line healthcare providers.[41] Multiple trips were made to northern Saskatchewan to foster collaborative relationships, conduct home-based visits to pilot test assessment protocols, and collect normative data for Aboriginal adults. This work was conducted in partnership with a family physician and Aboriginal homecare staff and managers, and included biannual workshops and telehealth conferences to revise test protocols. Ethical approval from the northern health region and community clinic was sought at each phase.

Telehealth-Delivered Support Group

This NET study involved the development and evaluation of a novel telehealth-delivered support group in response to the lack of supports reported by spouses of RRMC patients diagnosed with atypical, early-onset dementias such as frontotemporal dementias (FTDs) and the large geographical distances between rural caregivers.[42] Led by the RRMC clinical psychologists (M.O., M.C.), ten spouses of RRMC patients with atypical dementias (eight FTD) collaborated on the group's development and evaluation, including decisions about the frequency, format, membership, and aim (e.g., emotion processing vs. psychoeducational). Members agreed on monthly 90-minute meetings, conducted via telehealth videoconferencing. Multiple data sources were used to assess effectiveness of the group, including a face-to-face workshop held after 18 months. Group members were active partners in the research design, data collection, interpretation, and dissemination.

The CBPR approaches used in these NET projects contrast with traditional "outside expert" approaches where

researchers determine the study questions, methods, tools, and interventions[8] and which are characterized by detachment between researchers and communities.[1] These projects also reflect a commitment to action that is a hallmark of CBPR.[8] The studies had a significant impact on the development of the research program by raising the profile of rural dementia care research, developing community partnerships, exchanging knowledge, building collaboration among researchers, enhancing researchers' skills as co-learners, and establishing the groundwork and priorities for future research.

BUILDING ON THE MOMENTUM

With current support from a 5-year Applied Chair in Health Services and Policy Research funded by CIHR and the Saskatchewan Health Research Foundation (2009-2014), the team has built on the NET's momentum and CBPR approach with a program that focuses on *Healthcare Delivery Across the Continuum for Rural and Remote Seniors with Dementia.* We adapted the NET conceptual model to include the required components of research, mentoring, and knowledge exchange. Researchers were challenged with creating an environment of collaboration and exchange with health system managers and policy makers to support the application of research into policies, programs, and practice. The grant required a strategy to involve intended knowledge users "early and often."

We operationalized this mandate by developing a Decision-Maker Advisory Council, drawing on relationships with individuals and organizations that were established during our previous research. The 27-member council brought together family caregivers, front-line staff, facility and home care managers, regional health authority directors, provincial Ministry of Health consultants, family physicians, the Alzheimer Society of Saskatchewan, community partners from individual projects, and leading researchers from Canada and internationally. The council terms of reference are to provide ongoing direction in all phases of the research-to-action cycle, from identifying research priorities to developing policy implications. Council members unanimously agreed that, at minimum, a yearly face-to-face meeting was essential for ensuring active participation. Since October 2008, we have held an annual knowledge exchange Summit, attended by the Council (including community partners from individual projects in the larger research program), researchers (investigators, trainees, staff),

and other stakeholders. The Summit has helped to build and sustain partnerships between researchers and decision makers, and among decision makers from various sectors.

The format for the Summit is an informal, interactive, evening scientific poster session followed by a 1-day exchange meeting. Through presentations, interactive panel discussions, and small group work, the agenda is designed to engage network participants in discussion and decision making about current issues in rural dementia care, research priorities, and research projects in various stages of development. Decision makers are active participants, giving presentations, leading discussions, and showcasing best-practice initiatives in their organizations. Throughout the year, individual project teams have ongoing interaction with their decision-maker partners. Participants complete a brief evaluation at the end of each Summit that is used to ensure that the event remains meaningful. A Summit report is sent to participants and posted on our website. A newsletter providing updates of chair-related projects, new resources, and other relevant news, is mailed to council members mid-year and again posted on our website.

BENEFITS OF A CBPR APPROACH

Identified as benefits of CBPR,[2,9] involving community partners in the full research process has improved the quality, relevance, and application of our findings. Two-way exchange processes that occur over time and give equal importance to what researchers and decision makers can learn from each other, can produce cultural shifts that facilitate the ongoing use of research knowledge in decision making.[43,44] Our partners have shaped the research focus, specific interventions implemented, research designs used to evaluate them, and dissemination of findings. In developing the RRMC, the community meetings improved our understanding of community needs and priorities, which led to two primary changes in the design of the RRMC evaluation. The researchers had proposed a between-group (telehealth vs. in-person) randomized design in which half of the communities with existing telehealth infrastructure would be assigned to standard (in-person) care. However, participants advised that designs that did not use telehealth would jeopardize stakeholder buy-in because of the perceived desirability of using telehealth. Physicians in remote northern communities reported that they would be unlikely to refer patients because of the extreme financial

and transportation challenges of traveling up to 500 km for patients randomized to the in-person control group.[45] Based on this information, a single case design was adopted, in which patients alternated between telehealth and in-person follow-up. The second change was to offer northern patients telehealth for all follow-up visits, thus treating the six remote northern communities as a separate, descriptive substudy. Additionally, we learned that issues of dementia care in remote northern Saskatchewan are different from rural areas, which led to graduate student thesis projects investigating dementia care from the perspective of nurses working in remote northern health facilities[46] and exploring access to dementia care services by northern residents.[47]

Using data to inform action that benefits the community is a key principle of CBPR[8] and sustainable impact is a characteristic of successful partnerships.[48] An example of these principles is the transfer of the RRMC research project to a sustained program funded by the Saskatchewan Ministry of Health, which we attribute in large part to early community and ministry involvement. Securing program funding was challenging and time consuming, and compounded by our lack of understanding of how such policy decisions are made. Without guidance from our partners, this transition may not have been successful. The FTD support group provides another example of CBPR facilitating translation to a sustainable program. Group members' desire to advocate for system changes to address the challenges that they had faced led to a powerful panel presentation at the annual Summit. At the end of the day, group members met with the leadership of the Alzheimer Society of Saskatchewan to lobby for new programs. In response, the society has recently adopted the telehealth-delivered FTD support group model for a province-wide program. Because of high demand, the society is now running two support groups co-facilitated by one of the team psychologists (M.O.), who will step back after an initial transition phase. Our partnership has strengthened the society's capacity to deliver a much-needed service. A lesson learned in this study was that the active involvement of the society even earlier in the demonstration program would have facilitated this transfer. (See O'Connell et al.[42] for more details about the FTD group development process and evaluation results.)

Facilitated by the researchers and funded by the research program, three videos were created in which FTD support group collaborators describe their caregiving experiences. One of the collaborators is also featured in a video describing a program of interactive activities that she developed as a response to her husband's need for engaging activities consistent with his abilities. The videos are additional outcomes of our collaborative research, resulting in capacity building and empowerment of our partners. These knowledge exchange tools can be found on our team's website and on YouTube.

Additional strengths of CBPR are that it joins partners with diverse skills, knowledge, and expertise to address complex problems.[2] Diverse membership[48] and broad-based support[2] facilitate successful CBPR. Our program's Advisory Council brings together a wide range of knowledge users that provides broad direction to the overall program. The individual projects have fewer (and thus less diverse) partners, but the smaller groups facilitate coordinating of schedules and getting the work done, and reduce costs. We have learned that there is synergy in having both larger and smaller groups of partners with overlapping membership, and providing a venue (annual Summit) to bring them together. Having two levels or types of partnerships (the Advisory Council and individual project partners) also allows for leadership at multiple levels, another feature of successful CBPR.[48] It also helps to address the question of who represents the community and how community is defined.[2] This partnership model could be applied in other settings where large research programs with multiple sites or subprojects are being conducted.

CBPR also improves the quality and validity of research by incorporating local knowledge.[2] Engaging spouses of FTD patients in creating and evaluating a telehealth support group, and partnering with a local physician and front-line Aboriginal healthcare providers in developing and testing culturally appropriate assessment tools, improved the research quality and validity by involving those affected. CBPR can bridge cultural gaps and help to overcome distrust of research by communities that have been the subject of research in the past.[2] These strengths were particularly important in the research with Aboriginal partners. Additionally, CBPR can strengthen partners' research and program development capacity.[2] In 2011, we conducted an in-depth evaluation of the Summit, in which our partners reported that they value the opportunity to influence the direction of research, learn about research methods and current best practices, and net-

work with researchers and other decision-makers across a wide range of sectors. The Summit model could be adapted to other research settings and programs.

CHALLENGES OF CBPR

As noted throughout the paper, and as reported by others,[2,5] there are challenges associated with CBPR approaches. These include conflicts associated with differences in priorities and finding a balance between research and action. For example, in planning the RRMC evaluation, the researchers proposed a randomized, controlled trial, but community partners identified serious potential problems with this design. Finding an alternative that was scientifically rigorous and acceptable to both the community and a large interdisciplinary group of researchers from different research traditions was a challenge, but resulted in essential design modifications that permitted the research to go forward while strengthening trust and open communication among the team members. Another challenge was balancing the FTD support group members' desire for advocacy and immediate action to assist others in the community with the very real limitations in professional resources, and the need to carefully evaluate the telehealth support group to design an effective template for future interventions. The nontraditional structure of the support group that included the group members as research collaborators and co-authors facilitated true knowledge exchange, which fostered the development of advocacy skills among the clinical researchers and an enhanced appreciation of the factors that contribute to high-quality clinical research by the spousal caregivers.

Recommendations for improving the success of CBPR include planning ahead for sustainability.[48] Although we have had successes in sustainability, there have been system- or policy-related challenges. The governmental policy of requiring Mini-Mental Status Examination scores to determine eligibility for funding of cholinesterase inhibitor therapy is a barrier to broad implementation of the Northern Cultural Assessment of Memory tool.[41] Developing a strategy to challenge this policy requires research into its history and source, and a long-term effort to lobby for change, which to date we have not had the time or energy to pursue. In retrospect, the evaluation of the Enhancing Care program[30] (NET study) would have benefited from a CBPR approach, by involving facilities and the Alzheimer Society in addressing the identified problems in program delivery and sustainability. However, as a student thesis project, the additional time and resources needed for a CBPR approach were barriers.

CBPR is time- and resource-intensive and requires a long-term commitment to build relationships and trust.[3] To ensure that knowledge exchange events such as the Summit are meaningful and productive, and to maintain other communication strategies such as our website, considerable time and resources are needed. The health care context is one of constant change, resulting in numerous competing demands for the time, energy, and resources of decision makers. Maintaining relevancy to their work and health region priorities, and supporting travel costs, especially for family members, facilitates participation. The increasing recognition and funding for integrated knowledge exchange strategies by research funding agencies has helped in maintaining regular, face-to-face contact with our decision makers. Because of the rural focus, many participants must travel long distances, and such expenses need to be covered.

Funding and sustaining research that is dependent on community partners can be difficult owing to their limited resources. Meshing the timelines of the grant submission process with regional planning and budget cycles can be a challenge. Ideally, longitudinal research should include more than one decision maker from each region or community to maintain continuity in case of turnover. There has been remarkable continuity, particularly in the project-specific advisory groups, but some members of the larger Advisory Council have retired or changed positions. With this larger group, it is more difficult to maintain the same frequency of contact and level of participation. Although we do have gaps owing to attrition, many of those leaving have found their own replacement, an indication of their commitment. Research longevity helps to build this commitment, as does identifying partners who are passionate about the issues under investigation. A sign of the commitment of our network members is exemplified by a key rural regional manager who has moved into retirement and continues as a family member, who has made her story available in the televised media. As Israel et al.[2] have indicated, it is important to identify key community members who share the goals of the researchers and who participate in the development of operating norms, such as our joint decisions on the degree and type of communication and directions for future projects.

CONCLUSIONS

Our CBPR approach has evolved through three phases, with time frames that match our funding cycles. Over time, a process of mutual trust and respect has been building between our research team and our ever-widening community partners. With our relationship-focused leadership,[49] we have experienced few tensions and the time consumed has been enjoyable and worthwhile in terms of positive impact for the community we serve. Using the typology proposed by Arnstein,[50] our engagement with decision makers has evolved from "consultation" to "partnership"; factors such as researcher accountability to funding agencies and limitations of researcher expertise are challenges to reaching the level of "citizen control." [50] We are developing a new CBPR initiative in primary health care for dementia in rural and remote settings, applying the lessons learned over 15 years. Experience has shown us that the CBPR approach is most likely to lead to sustained improvements in health service delivery.

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