Happenings

Dementia Care in Rural and Remote Areas: The First Year of a CIHR New Emerging Team

Debra G. Morgan, Norma J. Stewart, Margaret Crossley, Carl D'Arcy, Jay Biem, Andrew Kirk, and Dorothy Forbes

The Canadian Institutes of Health Research (CIHR) New Emerging Team (NET) program was designed to provide 5 years of support for the creation of new teams or the development of existing teams of investigators conducting collaborative multidisciplinary research in identified areas of focus. A NET group at the University of Saskatchewan was funded under the Cognitive Impairment in Aging focus for a project titled Strategies to Improve the Care of Persons with Dementia in Rural and Remote Areas. In this article we describe the research program developed by the team and implemented during the first year of our mandate.

Background

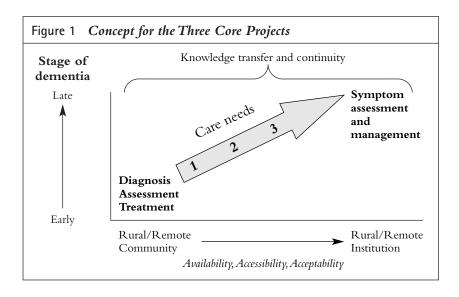
The prevalence of dementia in Canada is projected to double in the next 30 years (Canadian Study of Health and Aging Working Group, 1994). With 24% of Canadian seniors living in rural areas (Health Canada, 2001), there is a growing need for specialized dementia services and personnel. The availability, accessibility, and acceptability of services are critical factors in rural health care. Obstacles include low population density, long distances to travel, and lack of personnel with advanced training (Levin & Hanson, 2001). Data on dementia care in rural Canada are limited, but consistent themes in the available research include lack of adequate assessment services, shortage of specialized personnel and programs, and the need for caregiver education and support (Morgan, Semchuk, Stewart, & D'Arcy, 2002a, 2002b; Sarchuk & Wiebe, 1992).

The New Emerging Team Program: Criteria for Funding

NET applicants must demonstrate that the team brings added value that would not be possible if individual components were carried out as a series of isolated studies. Proposals must demonstrate that the integrated research program crosses at least two of the four CIHR themes, provide a plan to recruit new investigators, offer interdisciplinary training for graduate and postdoctoral trainees, and demonstrate the ability of the team to secure other funding. Teams must consist of three to six investigators at the outset, with the expectation that new team members will join in the first 3 years. At least two team members must have an established track record. Our initial team comprised six investigators representing four disciplines (nursing, psychology, medicine, and sociology/population health) and encompassed three CIHR themes (clinical, health services/health systems, and health of populations). Each member contributes a unique set of clinical and research skills to the team. The grant includes funding for New Investigator, doctoral, and postdoctoral awards.

Our NET Proposal

Our proposal included three "core" studies, aimed at: (a) improving the *availability* of specialized personnel and services providing assessment and management of dementia, (b) improving the *accessibility* of programs supporting formal and informal caregivers of persons with dementia, and (c) improving the *acceptability* of services for persons with dementia and their caregivers. Figure 1 provides a conceptual context in which to place



the core projects, which address care needs from early-stage to late-stage dementia. Overarching goals are knowledge transfer; continuity of care; and improved availability, accessibility, and acceptability of health-care services. During the first year of funding, three new co-investigators and six students have joined the team, enriching the multidisciplinary environment and extending the scope of research being conducted under the NET umbrella.

Rural Dementia NET Research Projects: Core Studies

- 1. Rural Memory Clinic and Telehealth Evaluation. This project involves the implementation and evaluation of a new Rural and Remote Memory Clinic aimed at improving access to assessment, diagnosis, and management of early-stage dementia. During the first 6 months of the project, team members held consultation meetings with care providers in all 14 rural and remote telehealth sites in Saskatchewan, to get feedback on memory clinic plans prior to implementation. Six of these sites are located in remote northern communities with primarily Aboriginal populations. We visited four of these northern communities again at the end of year one. Telehealth is used for pre-clinic assessment several weeks prior to a full-day clinic in a tertiary-care centre (Saskatoon). Patients are seen by a neurologist, a neuropsychologist, a geriatrician, and a neuroradiologist, after which a team case conference is held and a treatment plan developed. Follow-up assessments alternate between in-person and telehealth visits. Outcomes for patient, family, and local care providers are being evaluated.
- 2. Rural and Remote Dwelling Individuals with Alzheimer Disease: Prevalence and Utilization of Health-Care Services. This study examines characteristics of persons with and without dementia, and the impact of rural versus urban location on health-service use, using Statistics Canada data from the Canadian Community Health Survey.
- 3. Evaluation of a Dementia-Care Distance Education Program for Nursing Aides Employed in Rural Nursing Homes and Home-Care Agencies. We will evaluate the content and delivery format of a correspondence course developed by the Alzheimer Society of Saskatchewan.

Related Projects Developed by New NET Members

The neuroradiologist who has joined our team has external funding to evaluate magnetic resonance spectroscopy (MRS) in improving the accuracy of diagnosis and prognosis of mild cognitive impairment and Alzheimer disease. Memory clinic patients will undergo MRS on in-

person follow-up visits. A doctoral candidate in geography is exploring the impact of telehealth technology on health-care providers and will use the Geographic Information System to map clinic data. Because the consultation meetings held with northern providers revealed many barriers to accessing dementia services by northern seniors, a graduate student in Community Health and Epidemiology is exploring these issues. The lack of culturally appropriate neuropsychological instruments presents a challenge in detecting cognitive impairment and dementia in older Aboriginal adults. A doctoral student in psychology is modifying several existing assessment tools in collaboration with Aboriginal partners in Saskatoon and northern communities. Registered nurses' perceptions of issues in providing care to residents with dementia in northern institutions and communities is the focus of a doctoral student in nursing.

Several other studies have been undertaken by the NET group, all of them linked to the memory clinic. We are conducting a 5-year retrospective review of neurology and geriatric assessment unit medical records to examine referral patterns and clinical data on patients referred for assessment of possible dementia. Before opening the clinic we conducted a baseline telephone and mail survey of physician and non-physician providers in rural and northern Saskatchewan to examine community resources for dementia, provider exposure to clients with dementia, confidence in managing dementia, and continuing education priorities. A physiotherapy student has conducted a comprehensive literature review on gait and movement abnormalities in various forms of dementia, which was developed into a manuscript and has formed the basis of a protocol for assessing gait in clinic patients. Information on gait patterns has the potential to contribute to clinical care by distinguishing diagnostic subgroups in the early stages of the illness. A psychology graduate student has conducted a review of recent literature on diagnostic criteria for the major dementias and has developed a user-friendly manual to assist the memory clinic clinicians with the diagnosis.

The NET Effect

At the time of writing, our team has been working together for 1 year. Much effort has gone into launching the initial studies, as well as planning new projects that have emerged from the synergy of the multidisciplinary group. Despite the potential challenges of team research (e.g., scheduling difficulties, communication issues, diverse viewpoints to be reconciled, unequal pay-off for investigators), the benefits of working within a multidisciplinary environment are already evident. Team members have prepared 10 abstracts for conference presentation, three graduate students have been awarded external scholarships, and three

investigators have applied for external operating funds. The opportunity to travel to rural and northern communities to meet with local care providers regarding the memory clinic has been critical in developing the relationships required for successful research partnerships. By visiting these communities early in the research process, we were able to identify feasibility issues and address them in the study design before implementing the project. We expect continued productivity as our research program develops.

References

- Canadian Study of Health and Aging Working Group. (1994). Canadian Study of Health and Aging: Study methods and prevalence of dementia. *Canadian Medical Association Journal*, 159(6), 899–913.
- Health Canada. (2001). Statistical snapshots 2001: Seniors at a glance. Canada's Seniors Report #1. Ottawa: Division of Aging and Seniors, Health Canada.
- Levin, B., & Hanson, A. (2001). Rural mental health services. In S. Loue & B. Quill (Eds.), *Handbook of rural health* (pp. 241–256). New York: Kluwer Academic/Plenum.
- Morgan, D., Semchuk, K., Stewart, N., & D'Arcy, C. (2002a). Job strain among staff of rural nursing homes: A comparison of nurses, aides, and activity workers. *Journal of Nursing Administration*, 32(3), 152–161.
- Morgan, D., Semchuk, K., Stewart, N., & D'Arcy, C. (2002b). Rural families caring for a relative with dementia: Barriers to use of formal services. *Social Science and Medicine*, *55*(7), 51–64.
- Sarchuk, C., & Wiebe, P. (1992). Organization and coordination of services to individuals with dementia living in rural settings. In G. Gutman (Ed.), *Shelter and care of persons with dementia* (pp. 183–192). Vancouver: Gerontology Research Centre, Simon Fraser University.

Authors' Note

The initial New Emerging Team has been expanded since originally funded. New team co-investigators are: Lesley McBain (Sessional Lecturer, Department of Geography), Sheri Harder (Assistant Professor, Department of Medical Imaging), and Jenny Basran (Assistant Professor and Head, Department of Geriatrics).

We would like to acknowledge the funding partners who are supporting this research: CIHR Institute of Aging, CIHR Institute of Health Services and Policy Research, CIHR Rural and Northern Health Initiative, Saskatchewan Health Research Foundation, Alzheimer Society of Saskatchewan, and University of Saskatchewan. Travel support has been provided by Northern Medical Services (Saskatchewan).

Debra G. Morgan, PhD, RN, is Associate Professor and Chair, Rural Health Delivery, Institute of Agricultural Rural and Environmental Health, University of Saskatchewan, Saskatoon, Canada; and Principal Investigator, CIHR New Emerging Team. Norma J. Stewart, PhD, RN, is Professor and Associate Dean (Graduate Studies and Research), College of Nursing, University of Saskatchewan. Margaret Crossley, PhD, Reg. DPsych., is Associate Professor, Department of Psychology, and Director, Aging Research and Memory Clinic, University of Saskatchewan. Carl D'Arcy, PhD, is Professor and Director, Applied Research, Department of Psychiatry, College of Medicine, University of Saskatchewan. Jay Biem, MD, MSc, FRCP, is Associate Professor and CIHR Scholar, Institute of Agricultural Rural and Environmental Health and Division of General Internal Medicine, University of Saskatchewan. Andrew Kirk, MD, FRCP, is Professor and Head, Division of Neurology, Department of Medicine, University of Saskatchewan. Dorothy Forbes, PhD, RN, is Associate Professor and CIHR Scholar, College of Nursing, University of Saskatchewan.