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Dementia Care Networks' Study

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Louise Lemieux-Charles, PhD
Larry W. Chambers, PhD, FACE, FFPHM(UK)
Kevin Brazil
Rhonda Cockerill
Susan Jaglal
J. Kenneth Le Clair
Carole Cohen
Bill Dalziel
Barbara Schulman
Gertrude Cetinski
Marge Dempsey
Maureen Montemuro

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Principal Investigator:

Dr. Louise Lemieux-Charles
Department of Health Policy, Management and Evaluation
Faculty of Medicine
University of Toronto
12 Queen's Park Crescent W.
Toronto, ON
Canada M5S 1A8
Telephone: (416) 978-4210
Fax: (416) 978-6177
E-mail: l.lemieux.charles@utoronto.ca

Dr. Larry W. Chambers
President and Chief Scientist
University of Ottawa Institute on Health of the Elderly
SCO Health Service
Élisabeth-Bruyère Health Centre
43 Bruyère St. N.
Ottawa, ON
Canada K1N 5C8
Telephone: (613) 562-6036
Fax.: (613) 562-4266
E-mail: lchamber@scohs.on.ca

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For more information on the Canadian Health Services Research Foundation, contact the foundation at:
11 Holland Avenue, Suite 301
Ottawa, Ontario
K1Y 4S1
E-mail: communications@chrsf.ca
Telephone: (613) 728-2238
Fax: (613) 728-3527

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11, avenue Holland, bureau 301
Ottawa (Ontario)
K1Y 4S1
Courriel : communications@fcrss.ca
Téléphone : (613) 728-2238
Télécopieur : (613) 728-3527

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Principal Investigators:

Louise Lemieux-Charles, PhD ¹
Larry W. Chambers, PhD, FACE, FFPHM(UK) ²

Co-Investigators:

Kevin Brazil ³
Rhonda Cockerill ⁴
Susan Jaglal ⁵
J. Kenneth Le Clair ⁶
Carole Cohen ⁷
Bill Dalziel ⁸
Barbara Schulman ⁹
Gertrude Cetinski ¹⁰
Marge Dempsey ¹¹
Maureen Montemuro ¹²

¹Department of Health Policy, Management and Evaluation, University of Toronto

²University of Ottawa Institute on Health of the Elderly

³Department of Clinical Epidemiology and Biostatistics, McMaster University; St. Joseph's Health System Research Network, Hamilton

⁴Department of Health Policy, Management and Evaluation, University of Toronto

⁵Department of Physical Therapy, University of Toronto

⁶Division of Geriatric Psychiatry, Queen's University; Regional Geriatric Psychiatry Program PCCC, Kingston

⁷Department of Psychiatry, University of Toronto; Community Psychiatric Services for the Elderly, Sunnybrook and Women's College Health Sciences Centre, Toronto

⁸Geriatric Medicine, University of Ottawa; Ottawa Regional Geriatric Program; Care of the Elderly Program, SCO Health Service, Ottawa

⁹SCO Health Service, Ottawa

¹⁰Alzheimer Society of Hamilton

¹¹Alzheimer Society of Niagara Region

¹²St. Peter's Hospital, Hamilton

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Key Implications for Decision Makers

- Planning and provision of dementia services must respond to the nature of the illness and to the unique needs of and relationship between a care recipient and caregiver.
- Individuals with dementia and their caregivers are a high-risk population. Over 54% of care recipients and 25% of caregivers reported poor health days, and entry into the formal health care system is generally precipitated by a crisis.
- Dementia care networks enable the exchange of information about care recipients and caregivers. They also facilitate the development of new initiatives.
- Care recipients' and caregivers' perceptions of the effectiveness of dementia care networks are influenced by the availability of specialized services and the scope of services in the local community. In communities where specialized services are developed and agencies work together, networks are perceived to have changed the delivery of services through information sharing.
- The three most significant factors determining care recipients' and caregivers' satisfaction with care are coordination of care, awareness of services, and family physician care.
- The planning and provision of dementia care must:
 - Deal with the difficulty that care recipients and caregivers sometimes have accepting that a problem exists;
 - Provide care that addresses the physical, social, emotional, and financial status of caregivers and care recipients;
 - Help identify the most appropriate assistance required in consultation with different care providers, family members, and friends; and
 - Provide services in ways that allow for easy entry into and exit from the service system as care recipients' and caregivers' needs change.
- The greater the extent to which care recipients received emotional and informational support from members of their social support network, the more likely they were to report that they were satisfied with the processes of care.
- The more a caregiver is supported by in-home services, the more likely they are to report satisfaction with awareness and coordination of services. Lack of support for caregivers at risk may lead to the premature institutionalization of care recipients, thereby entailing higher costs to the health care system.
- At Community Care Access Centres in Ontario, the shift in policy away from providing homemaking and personal care will lower care recipients' and caregivers' satisfaction with care and increase costs for them.
- Where network members share multiple ties with members of different groups within the network they are more likely to perceive that the network has been effective in sharing facilities, joint training, shared administrative and client information, and the offering of joint clinical programs.

Executive Summary

Networks of care are seen as a way to overcome the fragmentation of services that can result from involving many different providers, types of care, and varieties of specialization. The Dementia Care Networks' Study investigated four community-based dementia care networks located in Ottawa, Toronto, Hamilton, and the Niagara region. Our research focused on the evolution, structure, and processes of the networks and on how these networks served the needs of care recipients and caregivers who were using community-based or ambulatory care services provided by acute-care agencies. A model of network effectiveness guided the study. The findings have implications for care recipients, caregivers, health and social service professionals, and government policy makers.

Though we studied each network as a whole, we also examined the relationships that existed among groups of agencies within them. The types of relationships we examined were based on activities related to administrative functions (e.g., shared programs) and service delivery functions (e.g., referrals received and sent). General findings indicate that members perceived higher administrative and service delivery effectiveness when network members shared multiple ties with members of different groups within the network (clique overlap) as opposed to the sharing of ties across the network. The centralization of network structure (i.e., the extent to which a network is dominated by a few agencies in terms of service delivery activities) was also found to be related to the perception of service delivery effectiveness.

Three major outcome variables were identified as they pertained to the care recipient/caregiver dyad: satisfaction with coordination of services; awareness of services; and satisfaction with family physician care. Care recipients' and caregivers' assessment of network effectiveness as measured by perception of and satisfaction with processes of care indicated that when care recipients receive emotional and informational support from members of their informal network, they are more likely to be satisfied with the care they are receiving. Caregivers, meanwhile, are more satisfied when the health care system increases the in-home services provided to the people for whom they are caring.

Specific findings related to network processes and outcomes included:

Service delivery indices of “case coordination” and “shared client information” were positively correlated with service delivery effectiveness. This suggests that care providers perceive service delivery to be most effective when case coordination and sharing of client information is concentrated within a few agencies.

The number of cliques in the “referrals received” activity was negatively correlated with both administrative effectiveness and service delivery effectiveness. This suggests that overall service delivery effectiveness decreases when agencies receive referrals only from the cliques in which they are involved.

Administrative effectiveness was positively correlated with clique overlap in the “shared administrative information” activity. This finding suggests that a high number of agencies involved in a high number of cliques facilitates the exchange of administrative information, which, in turn, enhances administrative effectiveness at the network level.

Clique overlap indices of “shared client information” and “joint clinical programs” were positively and significantly correlated with both administrative and service delivery effectiveness. This finding suggests that the degree of influence within cliques advances administrative and service delivery effectiveness.

Specific findings related to care recipients’ and caregivers’ perceptions of processes of care included:

The frequency of in-home services was positively related to satisfaction with coordination and awareness of services – the more in-home services a dyad received, the higher the level of satisfaction. The more hours a caregiver spent meeting the personal care needs of a care recipient, though, the less satisfied a dyad was with coordination. If a dyad was receiving help with personal care, both parties were also satisfied with the family physician’s awareness of services available for dementia patients.

Emotional support available to care recipients was positively related to both satisfaction with coordination and awareness of services; it did not influence assessment of physician services. Physical companionship available to care recipients was correlated with assessment of coordination; it did not influence opinions of awareness or physicians.

Satisfaction with coordination decreased with the hours of care provided by a caregiver, and increased with the emotional support received by a care recipient and the frequency of in-home services received by a caregiver.

Satisfaction with awareness increased with the age of a care recipient, assistance provided to a caregiver with personal care, emotional support given to a care recipient, and frequency of in-home services offered to a caregiver.

Satisfaction with physicians' care increased with a care recipient's age, when a caregiver and a care recipient were female, and when a caregiver received in-home help.

Method

We conducted a Care Provider Survey to evaluate service providers' perceptions of administrative and service delivery effectiveness, and a Steering Committee Survey to determine steering committee members' perceptions of the processes and outcomes of network management. A Care Recipient and Caregiver Survey gauged perceptions of and satisfaction with care processes. We supplemented this research with literature reviews as well as interviews and focus groups held with key stakeholders.