Summary of Activities in Initiative #6: Research on Caregiver Needs

Ontario's Strategy for Alzheimer Disease and Related Dementias

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Carrie A. McAiney, Ph.D.
Evaluation Consultant

OVERVIEW OF REPORT

The following report provides a summary of activities undertaken within Initiative #6 – Research on Caregiver Needs of Ontario's Strategy for Alzheimer Disease and Related Dementias.

OVERVIEW OF INITIATIVE

The goal of Initiative #6 was to undertake research in order to understand the issues and community support service needs of caregivers of individuals with Alzheimer Disease and related dementias (ADRD) in Ontario. It was expected that the research results would be used in the future to help improve community support services within Ontario.

The initiative was led by the Murray Alzheimer Research and Education Program (MAREP) in collaboration with the Alzheimer Society of Ontario (ASO) and the Caregivers' Association of Ontario (CAO). Together, a research plan was developed that included:

1. a review of the literature and
2. a research study involving caregivers from Ontario.

Each of these activities is discussed in greater detail below.

Literature Review

The literature review focused on three broad areas:

1. the characteristics of those caring for individuals with dementia in the community;
2. the experiences of dementia caregivers; and
3. coping strategies and community-based services used by caregivers to help them manage their situation.

In total, close to 800 research articles and presentations were reviewed. Based on this review, recommendations for future research in Canada, and Ontario specifically, were developed. The literature review and the corresponding recommendations are outlined in a report by Dupuis, Epp & Smale (2004).

Research Study – Details and Highlights

The research study involved two phases:

- Phase 1: a survey of caregivers residing in the community and
- Phase 2: focus groups with caregivers and care providers.

The primary goals of the survey were to gather information on:

1. the caregivers' careers as caregivers and the types of caregiving activities undertaken;
2. caregivers' awareness, use, level of satisfaction, and ability to access community support services;
3. the impact that caregiving has had on the caregivers and their families; and
4. the caregivers' informal resources and capabilities.

The survey targeted community-based caregivers of individuals with ADRD who resided in the community or had moved to a long-term care (LTC) home in the 6 months preceding the survey.

Since a comprehensive list of caregivers meeting these criteria did not exist, potential participants were identified using a variety of sources. The goal was to ensure that the final set of respondents were representative of caregivers across the province. The sources used to identify caregivers included:

- individual agencies across the province (e.g., local Alzheimer Chapters, the Caregivers' Association of Ontario, agencies providing services to caregivers such as the Red Cross, Adult Day Programs, VON and Visiting Homemakers);
- LTC homes (a sample of larger homes); and
- case managers with the Community Care Access Centres (CCACs).

Each of these sources was asked to distribute the questionnaires to caregivers meeting the criteria described above. Various media were also used to promote participation in the study.

Approximately 11,000 questionnaires were distributed. The researchers estimated that approximately 9300 reached community-based caregivers in Ontario. Completed questionnaires were returned by 2,244 caregivers, representing a response rate of 24.1%. This sample represents one of the largest samples of Canadian caregivers ever assembled.

In Phase 2 of the study, focus groups were conducted with caregivers and care providers to explore in detail, the issues identified from the survey results regarding the use of, and access to, community support services for caregivers. Fourteen focus groups were held in Spring 2002 – seven with caregivers and seven with care providers. The focus groups aimed to include a wide range of caregivers and care providers from all regions of the province including rural, urban and mid-sized areas, and regions where there had been a high response to the survey. Two focus groups (one for caregivers and one for care providers) were held in each of the following areas: Central Ontario, Northern Ontario, South Central Ontario, South Eastern Ontario, South Western Ontario, a large urban centre, and a predominantly rural centre.

The Alzheimer Chapters in each of these areas were responsible for recruiting caregivers and care providers for the focus groups. A total of 142 individuals were recruited (68 caregivers and 74 care providers). The focus groups ranged in size from 8 to 15 participants. Participants were also provided with an opportunity to provide additional written feedback after the focus group. Twenty-two individuals submitted written comments.

The information obtained from the focus groups and written comments was analyzed. Four main themes emerged:

1. Service delivery and systemic issues;
2. Human resource issues;
3. Public awareness and education for service providers; and
4. Caregiver empowerment and well-being.

A large working focus group was then held in September 2002 for caregivers, care providers, policy makers and planners. The purpose of this focus group was to develop recommendations and strategies for change based on the results of the caregiver survey and the focus groups with caregivers and care providers.

Potential participants were nominated by local Alzheimer Chapters and key agencies and organizations providing direct care or support to caregivers. In total, 20 caregivers and 23 care providers, planners and policy makers participated in the group, representing various parts of the province and various organizations and groups.

The care providers, planners and policy makers supported the caregivers in identifying recommendations and strategies that would help to ensure that all individuals with ADRD and their caregivers would have the necessary supports to maintain quality of life throughout the course of their disease.

Five fundamental principles related to the key areas of: systemic issues, human resource issues, and caregiver well-being were identified through the working focus group process. Adoption of these principles was considered necessary if the needs of those with ADRD in Ontario and their caregivers were to be met. The five principles were:

1. *A comprehensive and integrated community support system must be available to meet the needs of all caregivers and all people with dementia.*

2. *The community support system must be flexible and responsive to the changing individualized needs (i.e., physical, emotional, social, cultural) of both persons with dementia and their caregivers, throughout the disease progression.*

3. *All people providing care to persons with dementia must have specific and standardized dementia-related knowledge and skills.*

4. *An increased and stable workforce must be in place to provide continuity in dementia care.*

5. *Greater acknowledgement, recognition, and support must be given for the work that caregivers do.*

Smale & Dupuis, 2004b

In order for these principles to result in positive outcomes, 37 specific strategies were identified by the participants in the working focus groups.

The results from these research activities are summarized in detail in the following four documents:

Dupuis, S.L., Epp. T, & Smale, B. (2004). *Caregivers of Persons with Dementia: Roles, Experiences, Supports, and Coping. A Literature Review*. Murray Alzheimer Research and Education Program, University of Waterloo.

Smale, B. & Dupuis, S.L. (2004a). *In Their Own Voices: A Profile of Dementia Caregivers in Ontario. Stage 1:Survey Results*. Murray Alzheimer Research and Education Program, University of Waterloo.

Dupuis, S.L. & Smale, B. (2004). *In Their Own Voices: Dementia Caregivers Identify the Issues. Stage 3: The Focus Groups*. Murray Alzheimer Research and Education Program, University of Waterloo.

Smale, B. & Dupuis, S.L. (2004b). *In Their Own Voices: Guiding Principles and Strategies for Change Identified by and for Caregivers in Ontario. Stage 3: Working Focus Group*. Murray Alzheimer Research and Education Program, University of Waterloo.

These reports have been disseminated broadly and are available on the University of Waterloo website (www.marep.uwaterloo.ca).

REFERENCES

Dupuis, S.L., Epp. T, & Smale, B. (2004). *Caregivers of Persons with Dementia: Roles, Experiences, Supports, and Coping. A Literature Review*. Murray Alzheimer Research and Education Program, University of Waterloo.

Smale, B. & Dupuis, S.L. (2004). *In Their Own Voices: Guiding Principles and Strategies for Change Identified by and for Caregivers in Ontario. Stage 3: Working Focus Group*. Murray Alzheimer Research and Education Program, University of Waterloo.

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For further information or questions about the Initiative #6 evaluation, please contact:

Carrie McAiney, PhD
Assistant Professor, Dept. of Psychiatry & Behavioural Neurosciences
McMaster University
&
Evaluator, Geriatric Psychiatry Service
St. Joseph's Healthcare Hamilton
Centre for Mountain Health Services
Email: mcaineyc@mcmaster.ca
Phone: (905) 388-2511, ext. 6722