The Changing Role of Caregivers of Relatives with Dementia Living in Long-Term Care Facilities

by Lisa Loiselle, Research Associate, MAREP

Few researchers have examined how the roles of family members caring for relatives with dementia living in a long-term care facility change as the disease progresses. The Family Members of Persons with Dementia Project is a groundbreaking longitudinal study being conducted by Sherry Dupuis, Associate Director of Research for MAREP, and James Gladstone, Associate Professor in the School of Social Work at McMaster University.

This study has just completed its second year. Monies recently received from the Alzheimer Society of Canada will enable researchers to interview family members at least one more time. The additional data will enhance understanding of how the caregiver role changes over time and what factors affect those changes.

Family members recruited through two long-term care facilities in Southern Ontario include adult daughters, adult sons, siblings, spouses and other caregivers of persons with dementia. In year one (2000-2001), 47 familial caregivers agreed to share their experiences and in year two (2001-2002), 32 family members participated in a second interview. In this third year (2002-2003), researchers hope to interview as many as 29 caregivers still involved in the project.

Highlights of a preliminary report on findings from interviews conducted in year one and year two include:

• Caregivers reported that they helped with socializing, practical assistance, preserving family connections, preserving relatives’ dignity and self-esteem, assisting with personal care, and monitoring staff. In most cases, types of care provided did not change over a one-year span.

• Most caregivers described their relationships with family members living in long-term facilities as very close or close. Changes over the year included a role-reversal, where the adult child now felt like the “parent”; in relationships that were not previously close, the relationship deepened as the relative became more ill. Whether or not the relationship was close, caregivers continued to provide care.

• Interestingly, most family members (60%) did not think of themselves as “caregivers,” although 40% did. A common theme was the importance they placed on letting their relatives know that they still had family to love and care for them.

Caregivers have also provided information on their relationships with staff, negative and positive impacts of the role, how facilities might help them, and how all aspects of caregiving change over time.

The goal is to give family and other caregivers, as well as staff, a better understanding of the caregiving role in long-term care settings, and to develop specific strategies and recommendations for supporting caregivers. When the project wraps up at the end of 2004, results will be used to develop workshops and in-services as well as conference presentations and research papers. An executive summary of the final analysis will be available from Lisa Loiselle at (519) 888-4567, ext. 5040.
Fresh Faces at MAREP

Gillian Flynn, Research Associate
Gillian’s primary interests are in the areas of geriatric psychiatry and community health care. Building on her BSc in Psychology and Biology from Memorial University of Newfoundland, Gillian has completed an MSc with the department of Health Studies and Gerontology at the University of Waterloo in the past year. Welcome, Gillian, to the MAREP team!

Lisa Loiselle, Research Associate
Lisa’s strengths lie in qualitative research and program evaluation. Her interests include empowering individuals and communities through capacity building and involvement. She joined our team last November, armed with a BA in Psychology from Brock University and an MA in Community Psychology from Wilfrid Laurier University. Lisa has been working with Dr. Sherry Dupuis since 1999 on several projects focused on finding ways to support family members of persons with Alzheimer’s and related dementias. More recently, she has been involved in the Needs of Caregivers of Persons with Alzheimer Disease or a Related Dementia and Community Support Services in Ontario, Ontario’s Strategy for Alzheimer Disease and Related Dementias. Welcome, Lisa!

Philanthropists Extraordinaire
Ken and Marilyn Murray won top honours as outstanding philanthropists at the Waterloo Region and Wellington County 2002 Community Philanthropy Awards in the individual/couple/family category. Beyond financial contributions, they see volunteering as “a way to reinvest their years of cumulative experience back into the community.”

MAREP is one of Ken’s major projects. We are most grateful for the interest, enthusiasm and time he gives to the program. Congratulations, Ken and Marilyn!

A Changing Melody
A conference for persons with dementia and their partners in care
AUGUST 15-16, 2003, University of Waterloo
For the first time in Canada, persons with dementia and their informal partners in care will gather to learn from one another, as well as from experts, how to better cope with dementia and ultimately improve quality of life. MAREP is planning this conference with the Alzheimer Society of Canada, the Alzheimer Society of Ontario, and the Dementia Advocacy Support Network International. The organizing committee is fortunate to have persons living with dementia involved in the planning process: their invaluable expertise is crucial to the success of this conference. Watch for details in the spring issue.

Alzheimer Resource Manual
Care providers frequently comment that there is a need to understand …
• why residents with Alzheimer’s disease act the way they do
• what programs and interventions have been shown to be effective
• what can be done to enhance the quality of life for these individuals

The Alzheimer Resource Manual 2000 was created to respond to this need. This manual is a comprehensive collection of information about Alzheimer’s disease and other dementias, distilled from the research literature and from research activities. Representing the most up-to-date findings on diagnosis, treatment and care of persons affected by Alzheimer’s disease, the information is presented in point form and in simple language. The manual is intended for both formal and informal caregivers:

In long-term care facilities …
... staff from all areas — nursing, dietary, housekeeping, activity departments, as well as management and administration — will find useful information. The manual will be of particular interest to individuals who work closely with residents with some form of cognitive impairment.

In the community …
... the manual can help informal caregivers carry out their tasks with greater understanding of the course of the disease.

Contact Beverly Brookes to order your copy of the Alzheimer Resource Manual 2000. ($125)

Partnering with MAREP
MAREP has enjoyed successful partnerships with a number of long-term care facilities. In 2003, we look forward to working with:
• Homewood Health Centre Inc., Guelph
• Linhaven Home for the Aged, St. Catharines
• Marianhill, Pembroke
• Meadow Park Inc., London
• The Village of Winston Park, Kitchener

If you are interested in working with MAREP to improve the quality of life of persons with dementia, please call Cathy Conway.
Holistic healing and complementary therapies have become popular alternatives to more traditional medical interventions for dealing with problems related to the aging Canadian population. For long-term care residents, including those who suffer from various forms of dementia, horticultural therapy (HT) in particular has become increasingly popular.

Focusing on treating the resident as an individual, worthy of respect and dignity, HT promotes a natural sense of wellness through a non-invasive form of assessment and treatment. Using “living” materials — flowering plants, fruits, vegetables and herbs — this therapy stimulates thought, exercises the body, and encourages an awareness of the external environment.

According to Mitchell Hewson, a registered horticultural therapist with Homewood Health Centre in Guelph, Ontario, working with plants provides a tremendous outlet for people with Alzheimer’s disease and related dementias. It stimulates all the senses and inspires creativity. In HT classes, assessments and treatments are conducted in a natural environment: either a greenhouse or outdoors.

If you have a keen interest in exploring innovative approaches to care, MAREP’s spring conference is for you …

This conference is designed to illustrate the use of horticulture and complementary therapies to enhance the quality of life of people with Alzheimer’s disease or a related dementia.

Horticulture & Complementary Therapies
MONDAY, MAY 26, 2003, at the University of Waterloo
For details on conference registration, please contact MAREP (see page 4).

KEYNOTE ADDRESS: “Healing Through Horticulture”
Through special exercises and activities, this presentation is infused with the “voice” of a humanist and naturalist. Mitchell Hewson, the first registered horticultural therapist to practice in Canada, will address the dynamics of using horticulture as a therapeutic tool when working with persons with dementia. Socially, HT programs give residents opportunities to socialize and interact. Therapists can build rapport with residents in a non-threatening environment. Emotionally, activities such as cutting flowers, drying herbs, and making wreaths help improve skill level, self-esteem, and confidence. Gardening tasks such as pruning, smashing pots, and hoeing provide outlets for anger and aggression. Gardening stimulates memories of former gardens and old skills, enhancing cognitive functioning. Awareness of time can be promoted by modifying activities to accentuate particular seasons or holidays.

When tailored to meet the functioning levels of each individual, HT programs help rekindle the resident’s desire to engage in meaningful activity.

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Horticultural Therapy — An Alternative Approach
by Lisa Loiselle, Research Associate, MAREP
[Brief summary of articles by Mitchell Hewson titled “Horticultural therapy: a humanistic approach for residents with dementia,” published in Long Term Care (Nov/Dec 2001), and “Plant projects for patients with Alzheimer’s disease,” published in TLC … for plants (Fall 1991).]

“There is something magical and curative about the powers of nature as seen in the growth of a plant.”
Mitchell Hewson, Horticultural Therapist

HT also promotes the social, emotional, and cognitive functioning of persons with dementia. Socially, HT programs give residents opportunities to socialize and interact. Therapists can build rapport with residents in a non-threatening environment. Emotionally, activities such as cutting flowers, drying herbs, and making wreaths help improve skill level, self-esteem, and confidence. Gardening tasks such as pruning, smashing pots, and hoeing provide outlets for anger and aggression. Gardening stimulates memories of former gardens and old skills, enhancing cognitive functioning. Awareness of time can be promoted by modifying activities to accentuate particular seasons or holidays.

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WORKSHOP 1
Botanical Prints/Creative Arts for Dementia
Horticultural therapist Julie Martin will discuss HT planning/implementation, cognitive function assessment tools; she will guide you through a botanical print project.

WORKSHOP 2
Healing Gardens: An Inspiration
Landscape architect Virginia Burt will show that creating gardens is a journey of learning, of dreaming, and of understanding — particularly for people with dementia.

WORKSHOP 3
Aromatherapy for Specialized Populations
Keynote speaker Mitchell Hewson will also share his experience of using aromatherapy to enrich your clients’ lives and add a boost to your therapeutic programs.

WORKSHOP 4
Music Therapy and Dementia
Through music therapist Paulette Kydd’s interactive presentation, you will experience typical approaches and explore simple techniques that caregivers might use.
Innovations: Enhancing Ability in Dementia Care
is published quarterly by MAREP, an innovative program which integrates educational and research activities in an effort to improve dementia care practices in Canada. The goal of MAREP is to enhance the ability of care providers, both formal and informal, to respond to the needs of persons with Alzheimer’s disease and related dementias, and ultimately to improve the quality of life of persons with dementia and their families.

Beverly Brookes
Administrative Assistant

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Associate Director, Education and Administration

Sherry Dupuis, PhD
Associate Director, Research

Gillian Flynn, MSc & Lisa Loiselle, MA
Research Associates

Innovations is designed to provide accurate information. Although the information presented and the opinions expressed are gathered from sources thought to be reliable, their accuracy and correct interpretation cannot be guaranteed.

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MAREP is a Program of the Centre for Applied Health Research

Innovation in Action —“Functional Abilities Program”
by Eric Roy, Professor, Department of Kinesiology, Faculty of Applied Health Sciences, University of Waterloo

Funded by a community benefactor, the Functional Abilities Program (FAP) is a collaboration between the University of Waterloo and The Village of Winston Park. The program involves clinical specialists (on site at Winston Park) with backgrounds in kinesiology who are responsible for assessment and treatment planning, as well as a clinical coordinator (at the university, reporting to Dr. Roy) who supervises the clinical specialists and plans and implements research based on the data collected in the provision of FAP services.

FAP currently runs programs in the “nursing” and “retirement home” sections of Winston Park. In the nursing home, nursing staff and the house physician refer residents to FAP for problems such as falls, fractures, or declining mobility. Neurobehavioural assessments are carried out and intervention programs are developed. In the retirement home, neurobehavioural assessments are carried out on all consenting residents on arrival, and yearly thereafter. Individualized exercise programs are developed to treat any identified weaknesses. Weekly exercise classes are also run for “retirement home” residents.

Several other programs operate in addition to these assessment and exercise programs. Two of particular importance are designed to provide volunteer training.

The first program, Dignity, Awareness, Respect and Equality (DARE), was developed by a kinesiology undergraduate student as part of a research course. DARE gives potential FAP volunteers a basic background on the effects of aging and age-related neurologic and psychiatric disorders. Volunteers are also trained in carrying out various FAP treatment activities. We are currently running our second class of volunteers. Our goal is to have this program adopted as a requirement for persons wishing to volunteer in any long-term care facility in the Region of Waterloo, with the university and Winston Park acting as the training centre.

The second program, Family Partners in Care, focuses on teaching residents’ family members how best to work on various exercises such as walking and range of motion. This program extends the treatment time for the residents beyond what FAP staff would have time to do; as well, it gives families an opportunity to interact in productive and meaningful ways.