At present, a comprehensive portrait of caregivers of persons with dementia in Ontario is notably lacking. MAREP is currently partnering with the Alzheimer Society of Ontario and the Caregivers’ Association of Ontario to conduct Initiative 6 of Ontario’s Strategy for Alzheimer Disease and Related Dementias, which focuses on identifying the needs and issues of community-based caregivers who are caring for persons with Alzheimer disease or a related dementia. In particular, this study looks at their use of, and perceptions of, formal community support services.

In the first stage, a broadly based survey of community-based caregivers was undertaken between July and December 2001. Stage 2, involving a series of focus groups across Ontario with caregivers and care providers, is currently underway. The focus groups are designed to build on the results from Stage 1 with a focus on developing specific strategies and recommendations to help overcome the issues and difficulties faced by caregivers.

Preliminary analysis reveals that women continue to provide the majority of elder care in Ontario. About 30% of caregivers are 75 years of age or older. These caregivers are likely facing their own age-related issues.

Results also suggest that the caregiving situation, in many instances, is quite complex. Most caregivers are caring for persons with multiple medical issues; in other words, they are caring for a person with dementia as well as one or more long-standing illnesses or disabilities. Furthermore, almost one-third of caregivers are providing care entirely on their own, although most do receive some emotional and/or instrumental assistance from other family members and/or friends.

Typically, more than half of caregivers are not making use of formal community support services. Of the services that are being used, Meals on Wheels, home-maker services, in-home respite services, and adult day away programmes are used most frequently. Caregivers who use these services rate most of them as being quite helpful, particularly transportation, adult day away programmes, and out-of-home respite. Non-users, however, perceive these formal services as not being especially helpful. The reasons for these perceptions are being explored further in the focus group stage.

Caregivers perceive most community support services as being somewhat available, although users are likely to rate the services as more accessible than non-users. The most accessible services according to caregivers are Alzheimer disease support groups, Meals on Wheels, and adult day away programmes. When asked about the most difficult problems or barriers, caregivers perceive the number of hours of formal support to both caregivers and care receivers as inadequate to meet their needs. Further, they perceive that the health and social services system is difficult to navigate.

A final report should be available in December 2002; for more information, please contact MAREP.

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The Role of Leisure in Creating “Open Environments” in LTC Facilities
by Sherry Dupuis and Bryan Smale

Over 40 years ago, Goffman (1961) referred to long-term care facilities as “total institutions.” This approach emphasizes meeting residents’ needs solely within the facility, without the community resources, programs, and services normally comprising people’s lives.

Such “closed environments” result in reduction of personal choice and control, restriction of availability of resources, programmes, and services, and disintegration of ties to the community (Teague & MacNeil, 1992). Residents of long-term care facilities generally do not have opportunities to continue valued roles and activities in the community as well as relationships with people outside of the facility. They can thus become isolated, lonely, and depressed (Bitzan & Kruzich, 1992; Charron, 1992; Parmalee, Katz, & Lawton, 1992a, 1992b).

More recently, alternative philosophies and approaches to care have been emerging, resulting in a movement towards “person-centred” or “resident-focused” care and towards providing more “open environments” (Teague & MacNeil, 1992), such as those based on the Eden Alternative (Thomas, 1996). An open environment emphasizes the availability of a wide variety of options (i.e., resources, programmes, and services), freedom of choice to select options, open access to options and/or information, and maintenance of contact with the outside world (Teague & MacNeil, 1992). In short, the basic premise is that open environments are richer and more humane environments and ensure higher quality of life (Rowles, Concotelli, & High, 1996).

Maintaining connections with the community has many psychological and social benefits, such as feeling needed and a sense of contribution to society, feeling a sense of accomplishment, being able to continue to demonstrate abilities and strengths, having a sense of being connected to a larger group, and maintaining valued role status (Hutchison & McGill, 1998; Pedlar, Dupuis, & Gilbert, 1996). Yet, our understanding of how extensively such initiatives are being introduced in long-term care facilities and which factors might impede the provision of community access initiatives remains limited.

In this study, over 500 questionnaires were completed by activity directors across Canada. They reported on the types and frequency of various recreation programs offered within their facilities as well as their perceptions of benefits and constraints of these programs, and more specifically of community access programs.

The results indicate that in-house recreation programs comprise the majority of recreation opportunities offered, both in terms of the numbers of different types of activities as well as the frequency of provision. On average, all types of recreation activities and programs are offered 137.5 times in a typical month (SD = 103.4). Of all the offerings, community outreach and in-house community recreation programs represent on average only 15.8% (SD = 11.9) of the total provision, whereas in-house recreation programs make up 72.1%.

These findings suggest that the diversity of opportunities in recreation is not achieving levels expected in truly open environments. Consequently, the question turns to inhibiting or constraining factors.

Respondents perceived that lack of trained staff to support residents in the community, along with unwillingness of the family to give permission, limited the provision of community programmes. However, the barrier perceived to be the most limiting was the fears of residents in leaving the comfort and safety of the facility.

Recreation staff need to find creative and effective ways to address these challenges and constraints. Much more research is needed that examines other factors that might be impediting the creation of more open environments and identifies specific, effective strategies that might be used by recreation staff.

A final report including comparisons by region of the country should be available by July 2002. For more information, please contact MAREP.

References


Individuals with Dementia Can Learn New Information

by Kyle Whitfield, Research Associate, MAREP

Dr. Cameron Camp and his colleagues have been conducting research with individuals with dementia to determine the effectiveness of using a training technique called “spaced retrieval” to encourage the use of memory. They have discovered that individuals with dementia can still learn new information, which can in turn change their behaviour.

“Spaced retrieval” refers to a technique used to practice successfully recalling information at successively longer time intervals. For example, to help “Mrs. Jones” who asks over and over again when her sister will visit, Dr. Camp suggests showing her a posted message that indicates when her sister will be coming. This teaches her a process or procedure to retrieve information from an external place—in this instance, the message board. Eventually, she may be able to retrieve it by herself.

An intervention should be based on existing abilities in order to strengthen learning capacities. It cannot require new staff involvement; it cannot require huge amounts of training time; it has to be successful; and it has to be easy to maintain. Before designing an intervention, an important question needs to be asked: what channels for learning are still available to the person so she/he can get the answer for herself/himself?

Ultimately, the aim is to teach persons with dementia new skills and to reinforce forgotten skills. Dr. Camp and colleagues continue to conduct research in this area.

MAREP Study Improves Lighting in LTC Facility: Let There Be Light

by Timothy D. Epp, Postdoctoral Research Fellow, MAREP

The aging eye requires increased lighting to recognize objects and compensate for normal vision. Poor lighting in long-term care facilities contributes to resident insecurity, frustration and decreased quality of life. Adequate light minimizes frightening shadows, contributes to satisfaction of needs for nutrition and social interaction, and ensures safety for mobility and care practices.

Recently MAREP applied the lighting standards set by the Nursing Homes Act (1998) to an evaluation of one long-term care facility. We used a light meter to measure the quality of ambient (surrounding) light present in a room or area. Readings from three areas in a room (window, middle of room, and in a corner, farthest from window) were averaged to arrive at the room’s general illumination level. We also noted resident activities and the places in which they were spending the majority of their time, to ascertain whether the level of lighting was sufficient for these activities.

Overall, we found the lighting levels in this facility to be substandard. Some rooms had an inadequate number of ceiling lights, or staff failed to turn on all lights. A tub room and nursing stations lacked windows, and hallways contained dark alcoves. Little natural light entered the lounge areas. These conditions pose a danger for residents in their activities of daily living. As one resident from that facility remarked: “I don’t think there’s enough light, but maybe it’s just my eyes.”

To improve lighting in long-term care facilities, we suggest the following:

- ensure that all lights are turned on and curtains are open
- keep windows open where appropriate
- keep glass panes clean; replace light bulbs when they burn out
- install additional fixtures, such as dimming features or table lamps
- keep contrast to a minimum, ensuring that light is evenly distributed
- place light colours on top of dark; keep colour patterns simple
- vary the light as the day progresses, ensuring a clear day/night distinction
- ensure that objects are not left in hallways or other traffic areas

Working in Partnership with MAREP

MAREP has enjoyed successful partnerships with a number of long-term care facilities. In 2002 we look forward to working with Homewood Health Centre Inc. in Guelph, Linhaven Home for the Aged in St. Catharines, Marianhill in Pembroke, Meadow Park Inc. in London, and The Village of Winston Park in Kitchener.

Alzheimer Resource Manual

The Alzheimer Resource Manual 2000 is a comprehensive, easy-to-read collection of information about Alzheimer’s disease and other dementias, based on the most up-to-date research findings on diagnosis, treatment and care of persons living with Alzheimer’s disease. Please contact Beverly Brookes to order your copy. Cost: $125
Who’s Who at MAREP?

Meet the MAREP team!
Left to right: Dr. Paul McDonald, Kyle Whitfield, Dr. Sherry Dupuis, Beverly Brookes, Cathy Conway

Ken Murray
Founder and patron of the Kenneth G. Murray Alzheimer Research and Education Program

Innovations: Enhancing Abilities 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 disease and related dementias, and ultimately to improve the quality of life of persons with dementia and their families.

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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.

Newsletter Editor ~ Kyle Whitfield
Design and Layout ~ dejong publications

Education on Your Doorstep

Would you like to host an education series at your facility? MAREP offers you the opportunity to present a six-part educational program on the following topics:

- review of dementia
- medications and dementia
- challenging or responsive behaviours
- strategies for preventing and managing challenging behaviours
- person-centred care and creating positive environments
- a night out for caregivers

Each session runs approximately two hours. We suggest that you hold the sessions one evening per week, 7 to 9 pm, for six consecutive weeks. Participation in all sessions will entitle the attendee to a certificate.

If you’re interested in purchasing this series, please call Cathy Conway to discuss scheduling and payment options.

Our heartfelt thanks to the Long-Term Care Convention and Trade Show 2002 for giving us their raffle proceeds. This convention is organized by the Ontario Residential Care Association, the Ontario Home Health Care Providers Association, and the Ontario Long-Term Care Association.

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