



Innovations

Enhancing Ability in Dementia Care

A Publication of MAREP, the Kenneth G. Murray Alzheimer Research and Education Program

Ethnicity, Older Adults, and Long-Term Care

by Jessica Luh, Research Assistant, MAREP

Demographic changes in Canada are accelerating due to population aging and increases in immigration. The latter accounts for 53% of Canada's population growth (Canadian Heritage, 2003). According to Statistics Canada (2002), in 2001, 3.6 million Canadians were over 65 and 261,155 older adults were of a visible minority (Statistics Canada, 2003). Within the past 10 years, Canada's visible minority population has doubled; it will reach an estimated 15% in the year 2005 (Canadian Heritage, 2003). These immigration trends have prompted demographers to project an even greater increase in the number of older adults of varying ethnic backgrounds in the future (Statistics Canada, 2002).

Many older adults wish to "age in place" (i.e., at home). But increases in life expectancy, increased risk for chronic illness or disability, decreases in family size, and changes in gender roles and social institutions are reducing the viability of this preference. As family structures and roles evolve in ethnic communities (acculturation and assimilation), it is anticipated that more older adults and their families will turn to long-term care (LTC) facilities.

Given that many older minority ethnic adults may have "different values, beliefs and behaviours" (Tirone, 1997, p. 3) compared to dominant ethnic groups in Canada, LTC faces a major challenge. Workers in the health care system, other mainstream services, and the general community will need to be more knowledgeable, understanding, and sensitive to the personal and cultural needs of Canada's diverse older adult population (Hikoyeda & Wallace, 2001; Tirone, 1997).

Currently, little research has been focused on ethnic older adults and the use of health care services, such as LTC services and residences, in Canada. Most of the literature on LTC and older ethnic populations has been quantitative and has focused on utilization.

It is commonly believed that ethnic minority groups have extensive social networks that provide needed care; it is thought that due to preferences (e.g., wanting to be

close to home, fear of isolation and family abandonment) and/or barriers (e.g., discrimination, lack of English proficiency, and lack of specifically oriented services) ethnic minorities tend to use fewer social, health, and LTC services (Barresi & Stull, 1993; Chappell, 2001; Hikoyeda & Wallace, 2001). However, such assumptions will lead to a lower level of concern for developing and implementing services needed by the fastest growing and ethnically diverse population in Canada (Barresi & Stull, 1993; Chappell, 2001).

Furthermore, few studies have examined the perceptions of ethnic older adults who use LTC services (Hikoyeda, 2000). Studies that do exist have found disparities between what ethnic older adults perceive as important components of quality of life (e.g., services, staffing ratio or characteristics) and how family and administrators and/or staff perceive quality of life (Hall & Bocksnick, 1995; Hikoyeda & Wallace, 2001).

A critical component of providing quality care and services in community and LTC settings is understanding the individual values, needs, and life histories/lifestyles of ethnic older adults and their families. Currently, this may not be happening. A recent study found that both caregivers and care providers felt that the current LTC system in Ontario was unable to meet the individualized needs of persons with dementia and their partners in care, partly due to a lack of diversity of services cognizant of language and cultural issues and needs (Dupuis & Smale, in review).

"Ethnicity, Older Adults..." continued on page 2

INSIDE ...

- 2 ... Understanding Responsive Behaviours in Long-Term Care Settings
- 3 ... Co-op Education Makes the Grade
- 3 ... Safely Home at Last!
- 4 ... The Transition to LTC: How Staff Can Help

So, what's needed?

- 1 First, more qualitative research—whether at a broader level or within the LTC facility—is needed to better understand the meanings of quality of life and the values and overall needs of ethnic older adults. This will allow development and implementation of ethnically appropriate services and help determine sociocultural criteria to provide quality care (Barresi & Stull, 1993).
- 2 Second, policy makers, LTC providers, and community support service staff (e.g., CCAC staff) need to be more informed about the importance and impact of ethno-cultural factors (e.g., values and behaviours) in the provision and utilization of LTC services. This will result in increased cultural sensitivity (Allison & Smith, 1990).
- 3 Third, recruiting and hiring staff of diverse ethnic backgrounds in administrative and direct-care positions in the community and in LTC facilities can increase understanding of the needs of ethnic

older adults, reduce barriers to care provision, and better address the cultural needs of diverse groups (Dupuis & Smale, in review).

- 4 Fourth, staff both in the community and LTC settings need to develop meaningful partnerships with ethnic older adults, family members, and/or other members of the ethnic community. Respecting diverse knowledge bases and including these groups in policy development and the planning of programs and services will help increase cultural awareness and help ensure that our LTC system meets the needs of *all* older adults. As Barresi and Stull (1993) eloquently summarize, "planning, designing, implementing, and financing LTC programs and services will have to take into account the varied histories, cultures, circumstances, and needs of each of these [various ethnic] groups" (p. 18).

(References for this article available on request.)

Understanding Responsive Behaviours in Long-Term Care Settings: Research to Practice

by Lisa Loiselle, Research Associate, MAREP

Individuals with dementia often exhibit "challenging" behaviours: agitation, physical and verbal aggression, wandering, and vocally disruptive behaviours. The presence or absence of these behaviours can vary greatly from one person to another throughout the progression of the disease, for many reasons.

Sometimes these behaviours are related to changes in the brain that affect the person's memory and mood; in other instances, the environment may trigger the behaviour. Perhaps an activity, such as taking a bath, is too difficult. Perhaps the person feels physically unwell.

The term "responsive" behaviours is used to reflect a response to something negative, frustrating, or confusing. It places the reasons or triggers for challenging behaviours outside of the individual rather than within, recognizing that problems in the environment can be addressed and changed.

Suspiciousness is a typical response to the feeling that more and more is slipping out of control. Irritation builds quickly to anger as tasks that once seemed simple become difficult and confusing. Shadows, reflections, noises, normal room clutter, even the passage of time become puzzling, indecipherable, and terrifying. Internal sources of agitation such as pain, hunger, or being too hot or too cold are hard to identify. Medications may have unpredictable and unpleasant side effects; the medication as well as the dementia itself can cause sleep reversal. Often there is a compulsion to try to "find" something familiar to ease the feeling of being lost.

These behaviours can significantly impact family members, staff, other residents, and visitors to the

facility. More importantly, the behaviours can significantly decrease the quality of life of residents with dementia. It is, therefore, important to understand the frequency of these behaviours and find effective strategies for reducing them or coping with them.

In response to this challenge, MAREP is carrying out a joint research and education project with the Psychogeriatric Resource Consultants (PRCs) of Central South Ontario. Continuing work already undertaken, this study will examine staff members' perceptions of the nature of responsive (challenging) behaviours exhibited by the residents with dementia with whom they work, and identify strategies they perceive to be effective in managing these behaviours. A survey will be distributed to nurses, health care aides, recreation/activity staff, restorative care staff, occupational therapists and physiotherapists, and other support staff including dietary staff, housekeeping staff, maintenance staff, and service assistants. Data collection will begin in the fall of 2003.

Research findings will provide the basis for PRCs to develop educational tools that illustrate challenging behaviours and provide caregivers with practical strategies and interventions. Educational modules will also be developed for staff and family members in LTC settings, to increase awareness of responsive behaviours and to offer strategies that might help them cope.

Sources

<http://www.alz.org/PhysCare/Counseling/behaviors.htm>

<http://www.alzheimers.org.nz/fact7.html>

http://www.alzwa.org/ArticlesOnLine/articles_online.htm

Co-op Education Makes the Grade

by Bobbi Clifton, Co-op Student, MAREP

Four years of education, two years of work experience, networking opportunities, living in different cities, making money, acquiring interview and resume expertise ... all of this and so much more is available to those who study at the University of Waterloo.

The concept of co-operative education, introduced in 1957 at U of W, is well-received by employers. With 11,000 students in over 100 programs, U of W has the highest enrollment in co-operative education in Canada. Students from all six faculties on campus are involved in the “co-op process” that begins at the start of each term:

- *examining job postings—either online or at the William Tatham Centre for Co-operative Education*
- *preparing resumes and cover letters for each job application*
- *participating in job interviews with prospective employers*
- *waiting for a job offer*

Co-op students alternate work and academia—school for four months, work for the next four months, and so forth. So, yes, that means they have to go to school during the summer months—but the pay-off is enormous. Thanks to their co-op jobs, many students are able to pay for their entire education.

For the employer, students are a low-cost, temporary alternative to hiring full-time professionals. U of W students are motivated employees who can contribute in many ways. Upon graduation, many students are hired by their former co-op employers to work full time. This way, employers can avoid the exhaustive process of interviewing and training new staff.

Each term, MAREP hires U of W co-op students. This term each of the four Innovation Centres has a student

to assist with specific projects. I have been hired to work on-campus with the MAREP team on current education and research projects. Marlies van Tol, a Health Studies co-op student at Linhaven, feels that “working for MAREP is a great opportunity to learn about Alzheimer research.” She is quite happy working at one of MAREP’s Innovation Centres because it “...not only allows you to learn about research and education but it also gives you hands-on experience with people affected by Alzheimer’s disease.”

Recreation and Leisure student Cara Kleinknecht, currently working at Homewood, says, “I’m very thankful for my five co-op experiences and have really benefited from the program.” Cara is in her last co-op term and highly recommends the program. “Co-op offers you money to help pay for your education and, most importantly, the experience and contacts after you graduate,” states Kleinknecht.

Personally, I’ve been quite fortunate with the variety of co-op jobs I’ve experienced. This is my third work term, and I’m enjoying my placement here at MAREP. My duties vary based on the changing/evolving education and research projects in which MAREP is involved. Recently, I’ve been preparing sessions for the upcoming Education Series, updating the weekly Alzheimer’s Research Exchange (ARE) News Service, as well as contributing to the online ARE Education Module.

I think the best part about co-op is that you gain a breadth of knowledge that the classroom can’t teach you. My co-op jobs have given me independence and valuable opportunities. At times, co-op can be frustrating with the constant moving every four months and the extra work of applying and interviewing for jobs. (Somehow, every student seems to get two co-op interviews and a midterm on the same day—very stressful!) However, co-op education at U of W can provide a “real world” experience in addition to an excellent education.

Safely Home at Last!

People with Alzheimer Disease often lose the ability to recognize familiar places, to communicate, or to remember their names and addresses. They may leave home, become confused, and get lost. But there is help.

On October 8, 2003, Alzheimer Society of Canada launched Safely Home, a nationwide program designed to help find a person with Alzheimer Disease. In partnership with the RCMP, Alzheimer Society of Canada has developed a computerized registry accessible by police anywhere in Canada and the US.

Here’s how it works. The person with Alzheimer Disease wears an identification bracelet. If a loved one goes missing, the caregiver calls local police. Using

personal information provided by the caregiver, police access the database. A registrant is found when the information in the database matches the ID number on the lost person’s bracelet.

Over 14,000 Canadians are currently registered. Registration is voluntary and simple. For a one-time fee of \$25, the registrant receives an ID bracelet and cards. Wearing the bracelet and keeping cards in places such as wallets and coat pockets helps identify people quickly should they become lost.

To register with Safely Home, contact your local Alzheimer Society. Or visit www.alzheimerontario.org to find a Chapter near you.

The Transition to Long-Term Care: How Staff Can Help

by Gillian Flynn Reuss, Research Associate, MAREP

MAREP recently completed a research project that explored, from the caregiver's perspective, the experience of moving a loved one to a long-term care (LTC) facility. So how can facilities help ease the transition? Some recommendations, most of which came directly from caregivers interviewed in the study, are highlighted here:

prepare families

Explain the entire process more fully; provide checklists of key questions to ask, people to contact, and all items needed on the day of the move; teach families how to make visits more meaningful.

provide more time

Give caregivers more time to make a final decision about placement, and more time to transport and move their relatives into the facility.

individualize care

Respect and act upon the needs of residents and their families: allow admissions at the family's convenience; allow residents to eat meals with whomever they wish; and allow more personal items in each room.

provide a welcoming environment

Make caregivers and their relatives feel welcomed when they arrive at the facility; families could be met at the entrance and helped with the moving of belongings.

build stronger community connections

Maintain connections with day programs and local support groups to help the relatives adjust to the move.

educate staff

Sensitize the staff by educating them about the complexity of the transition process for some family members and raising awareness of the stress of caregiving.

provide family support

Provide support for families to help them deal with guilt, deterioration of their relatives' health, and sense of loss.

minimize the impact of transition

Provide support services for residents to deal with their feelings associated with the move. Also, to minimize the negative impact of the move to LTC, reduce the number of moves older adults make from one facility to another, and ensure placement on appropriate floors.

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

To be announced.

Associate Director, Education and Administration

Sherry Dupuis, PhD

Associate Director, Research

Gillian Flynn Reuss, 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.

Newsletter Editor ~ Beverly Brookes

Design and Layout ~ de jong publications

MAREP

The Kenneth G. Murray
Alzheimer Research and Education Program
Lyle Hallman Institute for Health Promotion



Waterloo, Ontario
N2L 3G1

Telephone

(519) 888-4567, ext. 6884

Fax

(519) 885-2694

E-mail

bbrookes@healthy.uwaterloo.ca

Website

www.marep.uwaterloo.ca

MAREP is a Program of the
Centre for Applied Health Research