



Improving Care Through Research

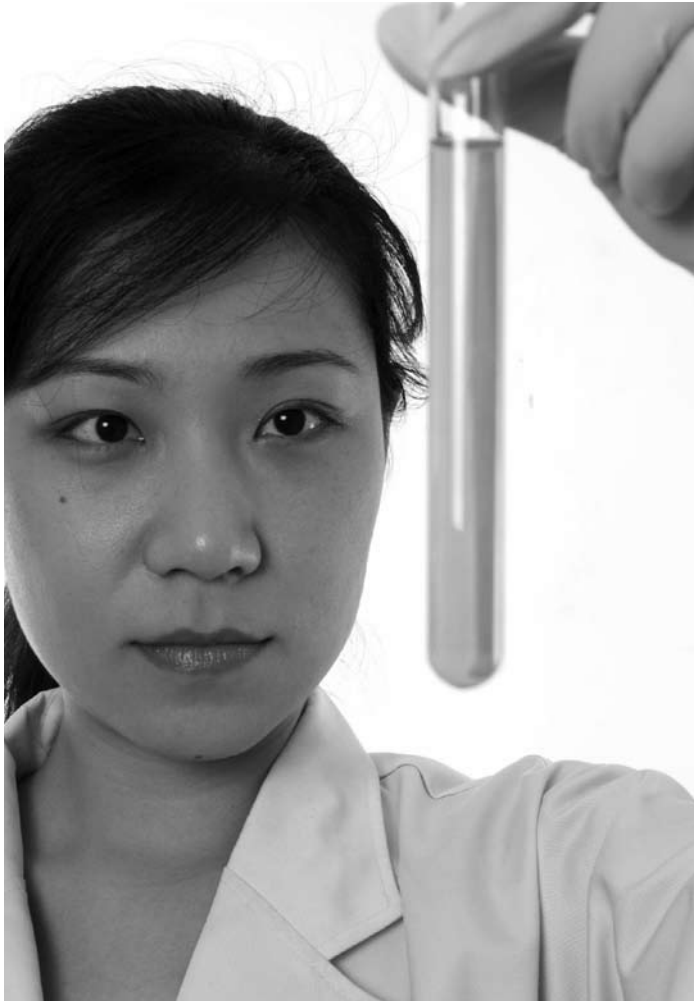
Enhancing
Quality of Life for
People Living with
Dementia

Alzheimer *Society*



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Introduction

Research into Alzheimer's disease and related dementias (ADRD) has made great strides in recent years, yet much remains to be done. Individuals and their families continue to live with the daily challenges of this difficult disease. As we await a cure, social and psychological researchers are focusing on strategies to assist people experiencing ADRD on a day to day basis, greatly enhancing their care and quality of life. Thus research into the social and psychological or quality of life aspects of Alzheimer's disease is extremely important. This report provides an overview of the social-psychological dementia research being done and identifies some of the impacts research is having on the lives of people with dementia, their families and caregivers.

Quality of life research is aimed at understanding and meeting the physical, psychological, emotional, social and spiritual needs of people with dementia. The Alzheimer Society is a leader in funding this research in Canada. Quality of life research supports our mission to alleviate the personal and social consequences of Alzheimer's and related dementias.

Quality of life researchers focus on helping people through the experience of living with Alzheimer's disease. Bio-medical researchers are seeking better treatments and searching for a means of prevention. The Alzheimer Society Research Program (ASRP) recognizes the importance of both approaches and funds research in both areas. Ultimately, all health research is about improving care. This document focuses on quality of life research funded by the ASRP. A companion document, *Report on Alzheimer's Disease and Current Research* summarizes a wide range of biomedical research taking place around the globe. It includes current treatment options and highlights some of the most promising leads now being investigated. It is available on the Alzheimer Society website www.alzheimer.ca (see Quick Links – Dr. Diamond's Lay Account).

THE CRUCIAL ROLE OF RESEARCH

Alzheimer's disease and other related dementias (ADRD) currently affect at least one out of every 11 Canadians over the age of 65. The prevalence of ADRD increases dramatically with age. The Alzheimer Society of Canada has released statistics from "Rising Tide – The Impact of Dementia on Canadian Society"; this study projects that, with the growing population of older adults, coupled with the fact that there currently is no cure for ADRD, there will be between 1 and 1.3 million Canadians living with ADRD in Canada within 25 years, Alzheimer's research, both quality of life and bio-medical, must be a priority if we are to lessen the devastating impact that this will have on individuals, families, healthcare systems and Canadian society.

1. The Alzheimer Society of Canada would like to thank Dr. B. Lynn Beattie, Dr. Maggie Gibson and Brenda Hounam for their thoughtful comments on this document.

The Personal Experience

THE VIEW FROM WITHIN

Direct involvement in research by people with dementia has been a key step in improving our understanding of Alzheimer's disease and related dementias (ADRD) and greatly enhances our ability to improve treatment, services, care and support, and, ultimately the quality of life.

“One of the most difficult aspects of this disease is the feeling that your mind has betrayed you.”

– Bruce

The study and treatment of dementia had rarely been approached from the perspective of the person with dementia before the 1990s. Since then, researchers have learned that individuals with mild to moderate cognitive impairment are able to respond consistently to questions about their feelings, concerns, and preferences, and to provide self-assessments of their health status and quality of life.

Today, people with Alzheimer's disease are sought as partners in research and have become advocates for themselves and others with ADRD. They now help develop research questions and approaches that better reflect the priorities common to them and their families. In fact, many indicate their sense of satisfaction in being able to make a meaningful contribution.

This new perspective is part of the gradual shift toward a more person-centred approach in care and research.

Research that examines the experience of dementia from the perspectives of those with ADRD enhances the understanding of such issues as:

- the unique needs of those living with ADRD at various stages of the disease;
- the experience of living with memory loss in various settings such as the family home, long-term care homes, adult day centres, and support groups;



- the continuing capabilities of people living with ADRD;
- the impact of formal care on one's sense of self;
- the “triggers” or factors that might cause stress or agitation;
- what “quality of life” means to people with ADRD and how to support maintaining the highest quality of life possible in various settings.

Researchers now know that people with dementia perceive quality of life factors quite differently from family members and formal care providers. When asked, they place emphasis on being useful, contributing to the world and to others, on having privacy and security and on self-determination and choice. Given this knowledge, finding ways to help meet these needs then becomes a research priority.

THE PERSON-CENTRED APPROACH HAS LED RESEARCHERS TO:

- recognize each person as an individual who deserves to be treated with dignity and respect;
- presume the person's competency; acknowledge the person's right to autonomy and self-determination;
- take into account the person's personality, life experiences, support systems, and ways of coping;
- understand that people with dementia are capable of learning and adjusting to their illness, contributing to their own care, and living meaningful lives.

INCLUSION AND INVOLVEMENT OF THOSE WITH DEMENTIA

After finding that leadership roles increased feelings of connection, well-being, and improved overall health for people with dementia, researchers began investigating how people with dementia could be included in organizations' planning and decision-making about health services and programs.

Effective inclusion was found to require action at multiple levels – by individuals with dementia, caregivers and friends, service providers and funding organizations.

Since the *Inclusion of Persons with Dementia into Health Services* study began, provincial and national organizations that work with people with dementia have adopted policies to promote inclusion. Although numerous barriers to inclusion still exist, there has been a documented increase in the number of people with dementia who are active and involved in community dementia support organizations as support group members and facilitators, committee advisors, guest speakers, panel representatives, book authors and newsletter contributors.

“I’M STILL HERE”

In what is possibly one of the most striking examples of how research into the personal experience of dementia is affecting change, two Ontario nurse-researchers found an innovative way to make their findings more accessible to others.

The researchers teamed with a playwright to create an innovative drama called “I’m Still Here” based on five studies: four conducted with people living with ADRD and one focused on the experience of daughters whose mothers were diagnosed with dementia.

A long-term study currently is being conducted to examine the impact of the play on audiences. Initial findings suggest that the play helps change images of dementia, broaden understanding of what it is like to live with memory loss, and trigger changes in how family, healthcare professionals and caregivers approach people with dementia. These changes will improve the quality of life of those whose lives

are touched by ADRD. The research has also been helpful in identifying strategies for translating research findings into practice.

The overwhelming success of the research-based drama led to the creation of a videotaped version of the play and accompanying teaching-learning guide that takes viewers through the key issues and themes reflected in the play.

Both are available at:

www.marep.uwaterloo.ca/products/still.html.

With a greater understanding of the experience of dementia from the perspectives of those living with it, more effective strategies can be designed to help people with ADRD become better self-advocates, improve their coping abilities, and live more meaningful lives, despite experiencing memory loss. This research is essential if care is to meet the unique needs of people with ADRD and ensure that their support and care are both effective and humane.



ENHANCING MEMORY, LANGUAGE AND DAILY LIVING ACTIVITIES

The primary symptoms of Alzheimer's disease are increasing memory loss followed by a reduced ability to think, understand, communicate, and make decisions. As people gradually lose their abilities and independence, their identity and sense of self-worth may be significantly damaged. It may also cause others to view them differently. Research suggests that people with Alzheimer's disease or a related dementia (ADRD) are keenly aware and concerned about the negative views of others about their impairments.

Alzheimer's disease results in decreasing abilities, increasing dependency, and often stigma and social isolation. It is not surprising that people greatly fear this diagnosis. In fact, Alzheimer's disease, along with heart disease, is the second more feared disease for Canadians as they age.

Recognizing the devastating impact that these changes have on people, much of the quality of life research looks at ways of preserving or enhancing a person's ability to think, communicate and function in their daily lives. These "non-drug" treatments include memory-stimulation and memory-enhancement programs, lifestyle programs, and nutrition interventions. Such strategies are especially effective when used in combination with drugs like Aricept, which help nerve cells in the brain communicate with one another. Combination therapies, in which drugs and "non-drug" treatments such as behavioural training are used together, are specifically designed for people with early-stage ADRD. The goal might be, for example, to improve their ability to name objects as well as their overall verbal communication.

Researchers are studying a condition known as Mild Cognitive Impairment (MCI). The majority of people with MCI go on to develop Alzheimer's disease within several years. Therefore, MCI provides an opportunity to examine the earliest changes associated with Alzheimer's disease. This will help identify signs, or what scientists call "markers," for memory loss and other cognitive problems. These markers could then help researchers develop more sensitive diagnostic tools, enabling people to begin treatment as early as possible.

EARLY INTERVENTION HELPFUL FOR DELAYING DEMENTIA

The findings of a very exciting study underway in Toronto indicate that an early intervention program that provides practical memory strategies and lifestyle education has the potential to delay the onset of dementia in older people with Mild Cognitive Impairment (MCI). The Memory Intervention Program is designed to help people and their families cope with and manage their day to day lives.

Participants are taught various memory strategies such as using a daily planner and carrying it with them to record names, phone numbers, and activities. They are also given information about the effects of stress, relaxation, nutrition and leisure activities on memory ability. Recent evaluations show that this type of early intervention helps people with MCI maintain their functional abilities longer thereby delaying the onset of clinical dementia. More information about this program can be found at <http://www.baycrest.org>.

Another common symptom of Alzheimer's disease and related dementias (ADRD) is the memory loss that is associated with disorientation. ADRD often impairs a person's ability to remember how to get to even the most familiar of places, such as a corner store or rooms within one's own house. This is an important safety issue, and safety is an area of intense interest to the Alzheimer Society. It is the reason behind the creation of the Alzheimer Society Safely Home® Wandering Registry. Safely Home® provides secure information to police that speeds up the search process when someone with dementia becomes lost, increasing the likelihood that they will be found quickly and returned home safely.

SPATIAL NAVIGATION IN DIFFERENT ENVIRONMENTS

A researcher funded by the Alzheimer Society has looked at how routes, distances and locations are remembered in various settings such as walking outside, reading a map, or navigating a videogame. Learning more about how people use information cues as they move from one place to another is the first step toward identifying strategies or tools that will help people with declining spatial memory find important routes.

There are many other areas of dementia research related to memory, communication, and function. Some researchers look at predictors of thinking impairment in later life such as delayed recall or a shrinking vocabulary. Others look at ways to understand and improve memory function, communication strategies, and attention span. Still others look at screening measures for dementia and the disease-related changes that happen in the aging brain. Again, combining these functional approaches with appropriate drug treatments is a growing area of interest in dementia research.

Research focused on memory, language and function provides a deeper understanding of changes associated with ADRD. It is critical to identifying ways to lessen the impact of those changes and help people function better despite dementia.

Informal Care

THE IMPACT ON FAMILY CAREGIVERS

With the rapidly aging population, more and more adults are finding themselves supporting and providing care for a family member or friend with Alzheimer's disease or a related dementia (ADRD). Caregiving can be intense and time consuming. It can continue for many years and have a major impact on caregivers' health and lifestyles. Thus, a major focus of social and psychological research is to examine the ways in which caregivers experience their role, as well as the ways in which they influence the lives of those with dementia. Compared to people who care for older adults with other health issues, caregivers of those with dementia are more likely to experience social isolation, chronic health problems, and depression. Physical, emotional, social, and financial demands on caregivers often increase as the disease progresses. Those who provide care to a loved one with dementia have had adverse health outcomes documented such as poorer immune response to influenza vaccines, slower wound healing, the development of hypertension and cardiovascular disease. Thus research into caregiving is of critical importance.

Researchers are working to find better ways to help the family adjust and adapt to the situation, to support all family

members and to assist them in continuing to live as normally as possible, despite the challenges associated with dementia.

Research programs in this area are helping to identify:

- the personal support and more formal needs of families and caregivers;
- effective coping strategies used by caregivers, such as planning regular breaks, preparing a list of specific tasks for people who offer help, and being realistic about the disease and their limitations as caregivers;
- how factors such as gender, age, ethnicity/culture and the relationship to the person with dementia impact the physical, psychological and emotional well-being of caregivers as well as their family relationships, finances, work, leisure time and social lives;
- the rewarding aspects of caregiving such as a sense of accomplishment, purpose, and meaning in life, personal growth, the ability to reciprocate care, personal fulfillment, and closer relationships, and how this helps them cope; and
- the ways that caregivers seek out and negotiate support from family, friends, and professionals.

Research into caregiving for a person with ADRD highlights the importance of education and training, social support, time away from the care role, and direct assistance with care in helping families adjust and cope. Most caregivers continue to feel isolated and alone. However, there are those who seek each other out to share information, form support groups, organize educational opportunities, and collaborate with organizations, agencies, professionals, and researchers. Finding ways to facilitate these activities is also a subject of research.

REACHING REMOTE FAMILY CAREGIVERS THROUGH INTERNET-BASED SUPPORT GROUPS

Supporting family members of people with dementia in rural and remote areas of Canada continues to be a challenge, so researchers set out to investigate whether family caregivers of people with dementia would benefit from an innovative internet-based support group.

After participating in ten weekly professionally-facilitated sessions, participants showed a reduction

in caregiver stress and overall positive response to the sessions. Research suggests that internet-based support group members in rural or remote locations are able to bond, share strategies for managing stress more effectively and provide support for each other. This research points to the potential of using technology such as the internet in supporting caregivers who do not have access to other services.⁵

Research demonstrates that, when families are supported and functioning well, they are able to better support the person with dementia and less likely to experience the negative health consequences so often associated with caregiving.

Nevertheless, getting the right type of support to those who need it is a challenge.

Researchers thus set about to create a practical tool to help in these situations.

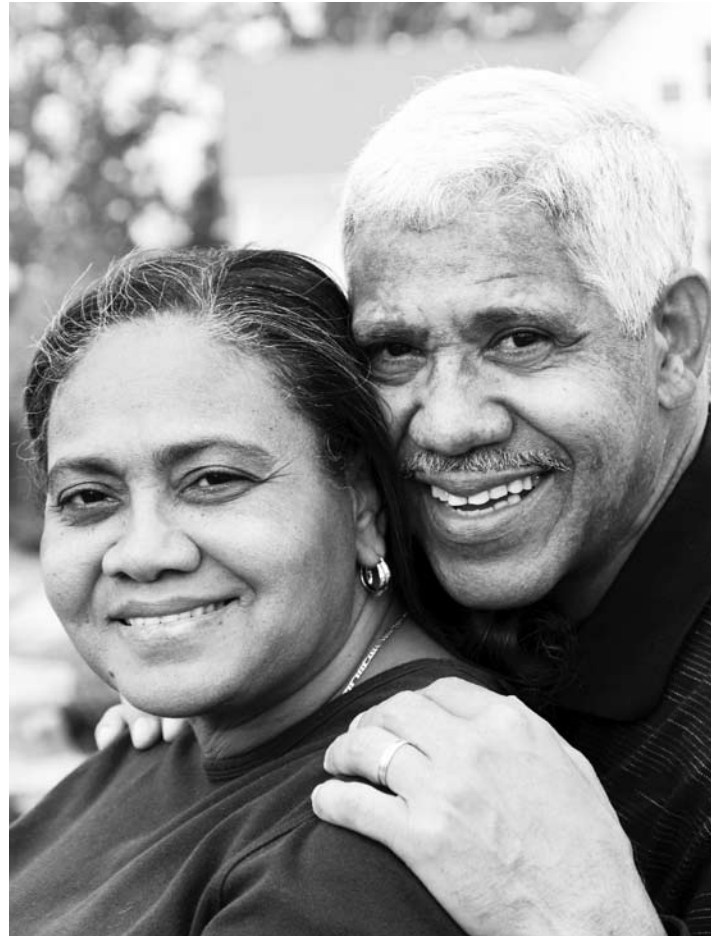
“This disease is a journey that my wife Pat and I are taking together. She has Alzheimer’s disease.”

– Ted

C.A.R.E. TOOL AND CAREGIVER RISK SCREEN

In order to lessen the stress experienced by caregivers of people with dementia, a method was needed to help evaluate the caregiving situation and identify the specific type of support or service that would be most beneficial to the individuals involved.

The initial study resulted in the development of two tools – the C.A.R.E. Tool (Caregivers’ Aspirations, Realities and Expectations) and the Caregiver Risk Screen. These tools can be used by home care professionals to evaluate the degree and urgency of risk to the caregivers and the type of intervention needed to support them, such as transportation services, financial aid, training or respite. Use of tools such as these help caregivers remain healthy and strong by identifying their needs more quickly.



Researchers involved in creating these tools are now evaluating how their use by home care professionals impacts caregiver well-being. At the same time, they will be looking at the most effective ways of implementing future tools into healthcare practices that support caregivers.

PAST RELATIONSHIP AND CAREGIVER HEALTH

Sometimes the issue of caregiving is further complicated by past family relationships. So it can be helpful to understand how a past relationship or a sense of duty or obligation influences the health of the caregivers. In general, women who take on caregiving even when the past relationship was difficult or even abusive, have poorer health outcomes. However, women sometimes do want the opportunity to provide care. Researchers are currently looking at the past relationships of women who care for people with Alzheimer’s disease and how this impacts their ability to care for their own health over time.⁷

IMPROVING CAREGIVER WELL-BEING DELAYS NURSING HOME PLACEMENT

Supporting the needs of a caregiver not only impacts the caregiver but has a very real impact on the person with dementia. An American study published in 2006 showed that improving the well-being of spouse-caregivers through support, delayed the need for nursing home placement significantly, up to approximately one and a half years, enabling their spouses to remain in their homes longer.⁸

Research into caregiving is particular timely given changes in the health care system and social services in Canada. Shorter hospital stays, longer waits for admission to long-term care facilities, and age-in-place initiatives put even greater pressures on families and friends to assume the caregiving role. At present, half of all people who have ADRD live in the community, most with family or friends.

Research in this area has led to a greater appreciation of the pivotal role that caregiving has on the life of the person with dementia, but also on the well-being and needs of caregivers themselves

The Formal Care System

MEETING NEEDS AT THE COMMUNITY LEVEL

In order to remain in their homes, people with Alzheimer's disease or a related dementia (ADRD) and their families rely greatly on formal healthcare and social support services. These services can have a very positive impact on how well people with ADRD and their family members cope. Yet, research has shown that between 40 and 60% of caregivers do not use existing services. Often this is because of difficulties in navigating the system but many people also feel that the services available do not address their needs. Either way, the research suggests that change is needed at the community level if we are to better meet the needs of those living with dementia.

Therefore a great deal of research is being done that focuses on the barriers to accessing needed support services and

resources and the effectiveness of different policies, programs, services, interventions, and models of care in reducing stress and improving quality of life for people with dementia and their family members.

Research on community-based formal care serves to:

- determine the type, intensity, and duration of health care and community support services that are needed to maintain well-being;
- examine the differences in and effectiveness of various health care policies and programs around the world (e.g. self-care and care delivered by others, consumer directed care, direct financial compensation for care provided by family, and tax credits and subsidies for families);
- investigate specific therapeutic interventions for the treatment and prevention of stress and depression;
- identify effective caregiving tools for coping with specific aspects of dementia such as responses to challenging behaviours and agitation, and enhanced communication skills;
- find ways to enhance the relationships between the informal and formal care systems.



ONTARIO DEMENTIA CAREGIVER NEEDS PROJECT

This is an example of the type of research being done to answer the question: are we meeting the needs of families caring for someone with dementia at the community level and if not, what can be done about it?

This study first identified the needs and gauged how well health and social support services were meeting those needs. A number of key limitations were revealed that make it difficult for caregivers to access services, many of which are urgently needed.

Researchers then used this information to develop a framework for better supporting caregivers known as the *Dementia Supportive Environment Framework*. By using this framework of fundamental principles, recommendations and strategies, policy makers can better address the needs of families affected by ADRD. Since its development, this framework for better supporting caregivers has been used to guide other important policy initiatives including the Ontario Roundtable on Future Planning for ADRD.

Although much still needs to be understood about the formal care system, one thing is clear: no single program, service, or intervention has been identified as a “cure all” for all of the stresses and complications associated with the experience of dementia. In fact, a range of formal support services and resources is needed for both the people with dementia and their families throughout the dementia journey.

IMPROVING QUALITY OF CARE AT THE INSTITUTIONAL LEVEL

There comes a time when the stresses of care become too great for most families to manage in the home, and the need for long-term care arises. The ability of long-term care homes to provide quality care is a concern that many Canadians share. Researchers working in this area are endeavouring to improve the quality of care in this type of setting and ultimately to enhance the residents’ quality of life.

Researchers study the design and implementation of various care models and evaluate their impact on resident care and

quality of life from the perspectives of staff members, family members, and the residents with dementia themselves.

For example, researchers:

- explore ways to ease the transition to long-term care for residents and their families;
- evaluate the impact of various psychosocial therapeutic programs and interventions such as therapeutic recreation and music therapy;
- consider how to enhance communication and specific care strategies (e.g., bathing, eating, etc.);
- develop and assess the design of dementia facilities to best support the continued abilities of people with dementia;
- examine issues related to end-of-life and palliative care;
- identify and solve ethical dilemmas in dementia care, such as issues related to substitute decision-making and sexuality;
- determine how to best support staff through education, continued professional development, higher job satisfaction, and staff retention; and
- examine the role of family members and how best to meet their needs in long-term care settings.

THE SHIFT TO PERSON-CENTRED CARE IN LONG-TERM CARE FACILITIES

Researchers and practitioners have been reviewing the traditional, highly routine, and task-oriented approaches to care known as the medical model. This work has led to the call for a culture change in long-term care, that recognizes and respects that each resident is a person, is more flexible, and takes into account each individual’s history, needs, desires, aspirations, and continued strengths. This is part of the person-centred care model.

This shift has the potential to significantly impact the quality of care, but how do you begin to change the culture in long-term care settings, especially given the lack of financial and staffing resources? Researchers examining this issue decided to test if a three-day course introducing best practices to front-line staff would be useful for initiating change.

LEARNING INITIATIVES IN LONG-TERM CARE – THE P.I.E.C.E.S FRAMEWORK

P.I.E.C.E.S. represents the Physical, Intellectual and Emotional health, the Centre-piece or focus of care, the Environment in which the person interacts and the Social self. The P.I.E.C.E.S. course uses a framework of common vision, language and approach to the care of older people including those with aggressive behaviours. P.I.E.C.E.S. promotes understanding of why a person behaves the way he or she does and the type of resources that are helpful in those situations.

When management supported and reinforced the education sessions, a reduction in challenging behaviours by residents was documented. P.I.E.C.E.S. was found to be a practical and effective approach to enhancing the ability of staff in long-term care settings to care for individuals and to continuously improve their care delivery. The P.I.E.C.E.S. program is now available as a model to help facilitate change toward a people-centred approach at long-term care facilities. See www.piecescanada.com/about.html for more information.

INDIVIDUALIZED CARE ASSESSMENT TOOL

Although individualized care is hailed as a “best practice” in long-term care, there has not been a reliable way to measure it, which makes it difficult to know if it exists or how much of it exists in a particular care setting. Researchers in Western Canada have identified “domains” of individualized care – such as resident autonomy and choice, staff-to-resident communication, and family involvement. After identifying the domains, they created a standardized tool for measuring them. The tool allows individualized care to be measured, compared and tracked over time. While further testing is required, this research tool marks an exciting step toward being able to assess the individualized care given to people with dementia and to evaluate changes to that care.¹¹

To further illustrate how the shift toward a person-centred approach impacts the care of people with dementia in long-term care homes; we can look at the psycho-social research being done on communication.



LEARNING FROM EXPRESSIVE COMMUNICATION

Researchers in British Columbia are looking at ways that people with dementia use their bodies to communicate their symptoms and needs. Researchers are using videotaped observations to learn about movement and expression, skills and habits, and social interactions of people with dementia. Whereas these people might typically be seen as non-verbal and unable to communicate, the people-centred approach spurs researchers to access the information they have to share. Even individuals who are well into the disease process can share their feelings and offer their perspectives if researchers recognize their non-verbal and expressive communication abilities.¹²

In an American study researchers discovered a link between agitated or uncooperative behaviour of nursing home residents with severe dementia and the language and tone used by their care providers. By observing reactions, researchers found that the residents were twice as likely to become agitated when they were spoken to in a kind of baby talk for seniors – by using a sing-song tone or patronizing diminutives like “honey” or “good girl.” The researchers observed that residents’ expressive behaviours (such as grimacing, clenching their teeth, groaning, crying or turning away) increased when they used this tone or made statements that assumed a state of dependency (such as “are we ready for our bath”). The study suggests just how

closely communication is linked to quality of care. It also suggests that despite severe dementia people retain an adult identity and dislike being treated otherwise.¹³

Eventually, all families are confronted by end-of-life decision making.

Researchers are now examining whether a booklet created for caregivers could be used by staff at long term care facilities to support families.

“I live a very active and full life so people are often surprised and disbelieving when I tell them that I have Alzheimer’s disease. . . I want to change people’s view of the disease. I’m no less a person now. I just have a physical disease that sometimes makes it difficult for me to access the information stored in my brain.”

COMFORT CARE AT THE END OF LIFE: A GUIDE FOR CAREGIVERS

Two Quebec doctors have developed a booklet entitled: *Comfort Care At The End Of Life For People With Alzheimer’s Diseases Or Other Degenerative Diseases Of The Brain*. The doctors used their research on the perspectives of family caregivers on end-of-life decision-making in developing the material. It answers frequently asked questions about the disease, decision making processes, symptom management at end of life, what to expect while the person with ADRD is dying, and grief.

Although not yet complete, the study on use of the booklet in the long-term care setting suggests that it can help to improve communication between staff and families, decrease family anxiety, increase family cooperation, and possibly cut down on the number of inappropriate transfers to hospitals. The booklet is a work-in-progress as research is continuing. In the meantime, it has been adapted to other languages (French, English, Italian, and Dutch) and to meet the unique religious, cultural, and legal circumstances of various areas.¹⁴

Social and psychological research efforts to improve the care system in communities and long term care settings have shed light on some of the caregiving practices of the past



that are now seen as inadequate or flawed. This has led to the development of alternative care approaches that allow people with Alzheimer’s disease or a related dementia (ADRD) to remain in their own homes for much longer, encourage and find new ways for people with dementia to be more active participants in their own care, and offer greater support to people with ADRD and their family care partners.

The Broader Community

SUPPORTING AND ENABLING PEOPLE WITH DEMENTIA

The implications for society of the growing number of people who will be affected by Alzheimer’s disease or a related dementia (ADRD) cannot be overstated. National Advisory Council on Aging has warned: “Some analysts believe that

Enhancing *Quality of Life* for People Living with *Dementia*

over the next 25 years, Alzheimer’s disease – together with other forms of cognitive impairment – will prove to have the highest economic, social and health cost burden of all diseases in Canada.” It is important to work now toward a planned and proactive response that enables people affected by dementia to enjoy greater consideration and inclusion in our society.

Some researchers emphasize the need to understand how the social, political, and built environment can serve to either enable or disable people with dementia and their families. These researchers look beyond individual concerns to the broader societal issues and the environmental and social barriers to empowerment. They determine how communities limit continued involvement by people with dementia and identify the changes needed to better support them and their families in community life.

Clearly a more informed society is needed to promote the well-being of individuals and families affected by dementia. There is a need for the creation of more enabling and supportive environments, and for stronger linkages among individuals, families, and community resources. Social and psychological research is contributing to each of these objectives in a number of meaningful ways.

RESEARCH IS HELPING TO CREATE MORE INFORMED SOCIETIES BY:

- developing and evaluating public awareness programs;
- exploring alternative ways to reduce the stigma and change images of dementia and approaches to dementia care, (such as the research-based plays and forums discussed here); and
- promoting healthy lifestyles, and identifying, promoting, and evaluating prevention programs like healthy brain initiatives.

RESEARCH SUPPORTS THE DEVELOPMENT AND SUSTAINABILITY OF SUPPORTIVE AND ENABLING ENVIRONMENTS BY:

- examining the physical environment with regard to the accessibility and accommodation needs of people with ADRD;

- evaluating ways to keep people with ADRD involved in their communities through advocacy, volunteering, supportive social environments and the establishment of innovative grassroots support systems for families such as Share the Care;
- investigating issues related to driving and transportation for people with dementia and their families;
- exploring the use and effectiveness of community programs and technology to assist people within their homes and communities and to enhance their autonomy, independence, safety, and security;
- examining workplace policies and practices that would better support people with dementia in their jobs for longer periods, and families who may need flexible work options or work leave;
- identifying approaches and policies that protect individuals from isolation, exploitation, and abuse; and
- examining the challenges of living with Alzheimer’s disease or a related dementia (ADRD) in rural and urban settings, and the impact of other diversity issues on the experience of living with dementia.

RESEARCH CONTRIBUTES TO THE DEVELOPMENT OF STRONGER COMMUNITY LINKAGES BY:

- developing a better understanding of the importance of continued community engagement and participation for people with ADRD, and identifying strategies to promote their involvement;
- examining the organizational factors needed to maximize “citizen in-put” from people with ADRD in planning and decision-making about services and programs; and
- finding ways to facilitate collaboration between informal and formal care providers and across the continuum of care as the disease progresses.

CARPE DIEM MODEL – ALTERNATIVE HOUSING OPTIONS FOR PEOPLE WITH DEMENTIA

One example of the type of research being done in this area involves creating a specially adapted housing unit (or “built environment”) for people with dementia. Based

on several years of research, an alternative approach to meeting the housing needs of people living with dementia was constructed in Quebec. Carpe Diem is a small, home-like residence entirely adapted to the needs of people with Alzheimer's disease and their family members. It is an example of a grass-roots initiative and a community working together to develop an innovative way of providing respectful care for people with dementia in the community. Carpe Diem is now a model approach for several communities in France, Martinique, Spain and Belgium and has won many awards for its humanitarianism and innovative approach to care.

This type of research leads to new resources such as the Perley-Rideau Guest House in Ottawa, which opened in March 2007. The Guest House is a home-like 12 bedroom bungalow providing short and long-term respite care from a few hours in an evening, to a couple of weeks. The program is designed for individuals with early to mid-stage dementia, and provides needed relief for the family caregiver. The project was born out of a partnership between Alzheimer Society of Ottawa, Carefor Health and Community Services, and the Perley and Rideau Veterans' Health Centre. (<http://www.prvhc.com/GuestHouse.aspx>)

Partnership approaches in healthcare that embrace the unique knowledge of all involved in care – including people with illness or disability, their families, and professionals – have been relatively slow to develop. Partnerships are critical to meeting the needs of individuals and families. Another example of the innovation that can arise from partnerships came in 2004 when researchers, educators, support and advocacy organizations, people with early stage dementia and their families came together to create the following unique annual event.

A CHANGING MELODY: A LEARNING AND SHARING FORUM

A Changing Melody was designed specifically by and for people with early stage dementia and their families. The first of its kind in Canada, the forum brings people with dementia and their family members together to learn from one another. Dementia care experts participate to

learn about how to actively improve the quality of life of people with dementia and their families. It also helps people realize that they are not alone. Researchers who evaluated the forum emphasized the importance of these learning opportunities for people with early stage dementia and their families who are living in the community. They can be effective in transforming meanings and images of dementia and in breaking the silence and reducing the stigma associated with dementia. Participants grow through gaining new knowledge and insights, connecting and identifying with others and building strong support networks, experiencing a new sense of hope, enablement and empowerment, and learning how to become strong dementia advocates.

Since its inception, A Changing Melody has received attention from Australia, Japan, the United States and the U.K. Findings from these studies have informed the development of A Changing Melody Tool Kit with the goal of assisting others in their communities to develop and implement similar forums. For information on this forum visit <http://www.marep.uwaterloo.ca/conferences/acm.html>.

The overall goal of these types of studies is to determine how people with dementia and their families are disadvantaged in communities and to identify effective ways in which to build better-informed, more supportive, and responsive communities. This research has enormous implications with respect to the ability of people with dementia to remain connected to their communities and to continue to live meaningful lives despite the progression of the disease.

Although the focus is on those with dementia and their families, research in this area has much broader societal implications. The creation of more enabling and supportive environments will likely benefit many others as well, such as those with chronic illnesses or disabilities.

Ensuring Quality Of Life For Future Generations

Much of the social and psychological research that has been conducted in Canada over the past several decades has provided critical insights on how to improve the quality of care and life for all those experiencing dementia. However, there are still large gaps in our understanding of dementia and dementia care, and much more funding for research is needed to ensure the highest quality of life for the increasing numbers of those who will confront dementia. Rigorous, sound social and psychological research now will help better prepare communities for the many more individuals and families who will be impacted by dementia in the future.

Research in the areas highlighted in this report will continue and expand as there is still much to learn. However, new areas of focus are also emerging. In the years to come, researchers will explore more fully the continuing *abilities* of those with dementia, and discover ways to support those abilities over time. They will investigate solutions and technologies to enhance the autonomy, independence and safety of people living in their homes.

Researchers will also examine the experience of dementia in specific population groups such as First Nations, people with Down syndrome, younger people with dementia (under age 65), and others who may have experiences or needs that are distinct to their situations. They will also investigate more fully the impact on young children of having a grandparent with dementia or a parent with early onset dementia.

Researchers will look for solutions to providing needs-based services that are not constrained by language, culture, geography or standard hours of service, and they will examine workplace policies for both people with dementia and their families. They will seek to answer very specific and practical questions such as “What are the staffing ratios needed to support person-centred care approaches in facility based settings?”

Conclusion

Alzheimer’s disease and related dementias (ADRD) affects a large portion of our aging population, their families and many younger people. While awaiting more effective medical treatments, prevention strategies, and ultimately a cure, Canadian social and psychological researchers are making great strides in improving care and quality of life for those affected.

THE ROLE OF KNOWLEDGE TRANSLATION

Knowledge translation is the process of transferring ethically sound research findings to those who can use them. The goals are to improve the health of Canadians, provide more effective health services and products, and strengthen the health care system. The process of knowledge translation is rather complicated, not only because the research and its findings may be quite complex, but also because different users have different needs. For example the needs of a research peer, who may base further research on previous findings, are likely to be quite different from those of a social worker or a caregiver. Thus, knowledge translation, although challenging, is also of key importance to improving the lives of those with dementia.

The research being conducted in Canada and elsewhere is diverse, often complex, and far-reaching. While some studies contribute to broad levels of understanding on societal-level issues, other studies help us to better understand the individual impact of living with dementia. Collectively, the insights gained from social and psychological research have made critical improvements in the lives of people with dementia and their family caregivers. While advancing our knowledge, they also point us in directions for future research.

The challenges we face today in providing person-centred care and support for people living with dementia and their families are serious. But these challenges are projected to increase dramatically and have a profound impact on individuals, families, and broader communities as the numbers of people diagnosed with ADRD soar over the next several decades. Within a generation, one quarter of all Canadians will have dementia in their families.

Much more research is needed in order to develop a comprehensive understanding of dementia and dementia care in Canada. Increased funding to support social and psychological research is required if we hope to ensure the highest quality of life for those who are currently experiencing Alzheimer's disease and other related dementias, and the many more who will develop these conditions in the future.

The Alzheimer Society of Canada is a leading financial supporter of Alzheimer research and training.

For a list of all recently funded ASC research projects, visit www.alzheimer.ca.

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