

Partnerships in Dementia Care Alliance (PiDC): **Bringing culture change to long-term care**

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The Issue:

As the Canadian population continues to age, more and more people will be diagnosed with an illness causing dementia. Currently over half a million Canadians (i.e., 1 in 11 older adults) are living with Alzheimer's disease or a related dementia (ADRD). By 2014 it is estimated that 50% more Canadian families will be facing ADRD, and by 2034, over one million Canadians will have some form of dementia.

The dramatic increases in the numbers of persons with dementia will have significant implications for those diagnosed and for their family members. It will also create a range of additional challenges for the provision of care in both community and long-term care (LTC) home settings due to the related communication, behavioural, and functional issues associated with dementia. Our broader communities and the LTC system specifically face significant barriers to providing quality care and support to those experiencing dementia and are often ill-equipped to address the unique and complex chronic needs of this growing population.

At the heart of the problem is a culture in long-term care that provides few opportunities for those directly involved in care to participate in decision-making. Current approaches to care often exclude persons with dementia from decision-making, fuelled by misunderstanding and stigma that view persons with dementia as incapable of communicating their experiences, and thus unable to make meaningful contributions to their own lives and the lives of others. These misconceptions contribute to the silencing and marginalisation of those with dementia and limit possibilities in dementia care.

Many have emphasized the urgent need to move away from the common top-down, provider-driven care approach to more client-driven and relationship-centred approaches. A shift is needed to a culture in new long-term care that is built upon strong bi-directional relationships and ensures that *all* key stakeholders including clients, family members, and staff are actively and meaningfully involved in planning and decision-making. This empowering, humanistic approach to care focuses on the experiences and needs of *all* involved in the care context and ensures that staff, too, are supported and well-equipped to translate research into practice.

Summary of Research:

The Partnerships in Dementia Care (PiDC) Alliance brings together researchers from five universities and 50 partners at the regional, provincial, and national levels representing all key stakeholder groups in dementia care (i.e., persons with dementia, family members, staff at all levels, dementia care specialists/educators, specialists in knowledge translation, a range of community and long-term care social support service agencies, policy makers, and a multidisciplinary team of co-researchers and students). The goal is to facilitate sustainable culture change in long-term care that reflects a relationship-centred/partnership approach to care and support for persons living with Alzheimer's disease or a related dementia (ADRD).

When the multiple voices and experiences of all involved in care are recognized, valued and incorporated in decision-making, the benefits are far reaching. Clients and their family members experience improved quality of care. The staff who work with them find their quality of work life enhanced. Health policies, programs, and services are more relevant to client and staff needs and, therefore, more sustainable.

The \$1.8 M project is buoyed by \$999,347 over five years from the Social Sciences and Humanities Research Council of Canada (SSHRC) in the form of a Community-University Research Alliances (CURA) grant. The support is complemented by approximately \$800,000 in staff, cash, and in-kind contributions from Alliance partners.

It is anticipated that the knowledge in partnership approaches and effective culture change processes gained by the PiDC Alliance will also have enormous potential for translation to a range of settings beyond dementia care. Resources developed throughout the project, including the *multi-perspective informed model and tool-kit for effective culture change in long-term care*, the *relationship-centred research and practice tools*, and the *education and training modules*, will be shared widely through the regional, provincial and national partners and with colleges and universities to translate learnings into curricula. These tools will be applicable to wider age-friendly/healthy community initiatives as well as to broader organizational change efforts.

“Funding for this study appropriately comes from the Community-University Research Alliances grant because it will truly make a difference to the community as a whole,” says George Dixon, Vice-President, University Research, University of Waterloo. “Given the astounding number of Canadian families who will face some form of dementia in the coming years, helping to facilitate this type of culture change couldn’t come at a more critical time. It’s also what our researchers do best – they find the answers to some of society’s most difficult questions.”

About the Kenneth G. Murray Alzheimer Research and Education Program (MAREP)

MAREP is an innovative program within the Schlegel-University of Waterloo Research Institute for Aging that integrates research and educational activities in an effort to improve dementia care practices in Canada and beyond. MAREP adopts a partnership approach, working with persons with dementia, family members, and professionals to enhance the well-being of all those involved in the dementia context and to promote the abilities and contributions of persons with dementia. For details, visit www.marep.uwaterloo.ca.

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