

Partnership in Dementia Care Alliance: Assessing the process of culture change in dementia care within diverse long-term care settings

The Partnerships in Dementia Care Alliance (PiDC) is a collaborative research project focused on improving the dementia care experience for staff, residents and family members in long term care. In 2009, the principle investigators, Dr. Sherry Dupuis (Director of the Murray Alzheimer Research and Education Program at the University of Waterloo) and Dr. Carrie McAiney (Department of Psychiatry and Behavioural Neurosciences at McMaster University) received support from the Social Sciences and Humanities Research Council (SSHRC) and over fifty different researchers, organizations and associations to undertake this project and join an Alliance of partners working together to enhance dementia care together. The Long Term and Continuing Care Association of Manitoba agreed to partner with the Alliance and research team in this initiative.

What is the purpose of this project?

- To facilitate sustainable long term care (LTC) culture change reflective of a relationship-centered approach in order to enhance the care experience for persons with Alzheimer's disease or a related dementia (ADRD), their family members, and staff in both community and LTC setting.
- To use a participatory action approach where members work collectively to achieve the ultimate goals of personal and social change, ensuring that the research is relevant to the communities being served.

Why is this project important?

- There is an urgent need for culture change in LTC, moving away from current top-down service provider-driven approaches to more client-driven approaches that:
 - Have strong bi-directional relationships where each participant is viewed as an equal
 - Ensures the involvement of all key stakeholders (clients, family members, staff, community members, partners, policy makers)
 - Provides humanistic approaches to care by focusing on the experiences of all involved in the care context, including clients, family members and staff
 - Values ongoing education for all staff to ensure that staff are well equipped in their jobs.
- Incorporating the voices of everyone involved in the care context in decision-making ensures that programs and services are relevant to client and staff needs and are therefore sustainable.

Who is participating in this project?

- Researchers from five different research settings (MAREP at the University of Waterloo, McMaster University, University of Windsor, University of Western Ontario, and Queens University) with expertise in dementia and dementia care will partner with organizations who support persons with dementia and their families in the community (i.e., Saint Elizabeth Health Care and the South West Community Care Access Centre) and LTC facilities (Bloomington Cove Specialty Care, Yee Hong Centre for Geriatric Care and Oakwood Retirement Communities) to undertake culture change initiatives within those settings.
- The researchers have partnered with a number of local, provincial and national organizations that will provide support to the activities through their participation in a Partnerships in Dementia Care Alliance (e.g., local Alzheimer Chapters, Psychogeriatric Resource Consultants, Registered Nursing Association of Ontario, Geriatric Clinics, Ontario Association of Non-Profit Homes and Services for Seniors, Ontario Association of Community Care Access Centres,) and disseminate research findings (e.g., Alzheimer Knowledge Exchange, Alzheimer Society of Ontario, Research Institute for Aging, Conestoga College, Seniors Health Research Transfer Network, Canadian Dementia Knowledge Transfer Network).

How will culture change occur?

- Each research site will establish a culture change coalition (CCC) including persons with dementia, family members, frontline staff, managers, researchers and students. The CCC will be responsible for all decision making related to the change process at each study site.
- The CCCs will use the Alzheimer's Disease and Related Dementias Planning Framework integrated with an Appreciate Inquiry approach - which focuses on the strengths and talents experienced by those in the settings - to help build on and sustain these strengths.
- The CCCs will operate using an Authentic Partnership approach which:
 - Recognizes how people with dementia have been excluded
 - Seeks to work in partnership with people with dementia
 - Views knowledge as power and education as a vehicle for social change
 - Incorporates a systematic process of critical reflection and dialogue in the community.

What are the anticipated outcomes of this project?

- This five-year project will expand our understanding of culture change, the factors that support and limit partnership and relationship-based approaches within different LTC settings, and develop a process to achieve positive outcomes at the personal, interpersonal and system levels.
- Our ultimate goal is to improve the quality of care and support for people with ADRD and their families and to improve the quality of work life for staff working in dementia care. Finally, the project will provide a rich research environment for the development of skills and building capacity within partnering organizations and for undergraduate, graduate and young researchers.

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