

Knowledge Translation

Promoting Self-Care through Knowledge Translation: A Way to Reach People with Early-Stage Dementia

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I have been conducting research among people with dementia for over 10 years now, and I am always struck by their thirst for knowledge about what I have learned from my research. Eager to share their own experiences of living with dementia, study participants also want to know how others are getting along, asking, “Is there anything you have heard from other people that might help me?”

Given the current enthusiasm for knowledge translation, it is timely to consider how to bring new knowledge to the people most immediately affected by dementia — those with the illness themselves. In the following few paragraphs, I will attempt to show that there is a growing population of people with early-stage dementia who could benefit from this kind of approach. In addition, I will present an overview of the research that would be of immediate benefit to this population in supporting their efforts at self-understanding and self-care. Finally, I will describe some of the guiding principles underlying knowledge translation strategies to engage with people with early-stage dementia.

Dementia is an umbrella term for a number of diseases characterized by progressive cognitive impairment resulting in functional disability. The most common of these diseases are Alzheimer disease and vascular dementia, which together account for about 85% of all dementia cases (Canadian Study of Health and Aging Working Group, 1994). The word *dementia* usually conjures an image of someone with profound disability living in a nursing home, but in fact at least 50% of people with dementia live in their own homes, usually for many years. The reported median lifespan for people with dementia ranges from 3.3 to 10.7 years after disease onset (Wolfson et al., 2001; Xie, Brayne, & Matthews, 2008), although that lifespan may be shifting with the advent of drug treatments intended to delay the onset or worsening of symptoms. The new med-

ications being developed tend to be most effective for those with mild impairment, a fact that has contributed to the increasing pressure to diagnose earlier in the disease trajectory (Alzheimer's Association, 2008). There is now an identifiable population living with what is usually referred to as early-stage dementia. These often relatively young people experience memory loss and some difficulty with everyday activities, but for the most part they are able to manage their symptoms and to continue living a meaningful life.

There is a growing body of knowledge about how people with dementia manage as well as they do. Those in the earlier stages of dementia may be very aware of their failing memory and its impact on their daily activities and social interactions (e.g., Clare, 2003; Harris & Keady, 2004; Harris & Sterin, 1999; Nygard & Ohman, 2002; Phinney & Chesla, 2003), and there is increasing emphasis in the literature on how they cope and adapt to these changes. When asked to express their own views on what is happening to them, people with dementia often downplay their difficulties and try to project a positive outlook, while at the same time identifying a variety of active coping strategies such as staying active, working harder, asking for help, and avoiding difficult situations (e.g., Clare, 2002; Menne, Kinney, & Morhardt, 2002; Nygard & Ohman, 2002; Pearce, Clare, & Pistrang, 2002; Phinney, 1998; Phinney, Chaudhury, & O'Connor, 2007; Preston, Marshall, & Bucks, 2007; Van Dijkhuizen, Clare, & Pearce, 2006; Werezak & Stewart, 2002). Overall, the findings from recent research tell us that while the disease itself presents many challenges, people in the early stages of dementia demonstrate considerable expertise in terms of how they understand and manage the effects of the illness in their everyday lives.

Researchers are beginning to disseminate this information through journal articles, books, and conference presentations, in an effort to reach clinicians, service providers, and, to a lesser extent, family caregivers, providing them with knowledge they can use to better support their patients, clients, and loved ones. However, at the same time, there is increasing eagerness within the research community to go directly to those living with the disease, reaching out to people with dementia to include them in the knowledge translation process so they might benefit more directly from the knowledge being generated.

This approach makes good sense given the extent to which people with early-stage dementia tend to "fly under the radar." These people typically do not seek out services (Toseland, McCallion, Gerber, & Banks, 2002), and their family members may not take on the role of caregiver until much later in the illness trajectory (O'Connor, 2007). This suggests that knowledge translation to benefit people with early-stage dementia will not readily occur through their contact with the health-care system

or through family caregivers; if it is to be effective at all, knowledge translation will have to be person-centred and community-based.

There is as yet little documentation of this work, with most efforts being at the planning or early implementation stage. While there is a clear need for further research, at this point it is worth identifying some of the principles guiding our own work in this area, drawing from a framework for knowledge translation that focuses on interactions between researchers and “user groups” (Jacobson, Butterill, & Goering, 2003).

The first principle is to take into account the fact of people’s cognitive impairment, recognizing that certain adaptations will be necessary to support new learning (Davis, 2005), such as providing information along different channels (written text, spoken word, visual cues, etc.) and reducing demands on recent memory (chunking information, use of repetition, etc.). We also want to explore how to draw on “care partners” in an appropriate way, identifying, for example, what friends and family members can do to help the person with early-stage dementia to become effectively involved in knowledge translation.

The second principle is to recognize that knowledge translation is not merely the passing on of new information. We believe, based on what has been learned from support groups and information forums for people with early-stage dementia (e.g., Morhardt, Sherell, & Gross, 2003; Murray Alzheimer Research and Education Program, 2007), that it is important for people to learn from each other and to engage in conversation about new research — not to just receive the information, but to talk about it and consider how it might apply to their own lives. The goal of this “dialogical” approach to knowledge translation is the creation of a community of researchers and people living with early-stage dementia who meet in a supportive group environment to learn about recent research and to exchange ideas about how to take it up in everyday life and how to then bring the reality of everyday life back into new research.

The third principle is to acknowledge that the emerging advocacy community can be an effective ally for researchers committed to engaging people who have early-stage dementia in the knowledge translation process. Knowledge translation is concerned not only with individuals acquiring the information and tools they need to support their own self-management efforts, but also with empowering them, as a group, to be informed about and supportive of each other’s efforts and to demand effective services. For example, Canadians have taken key leadership roles in the Dementia Advocacy and Support Network International (DASNI). These are people who have a diagnosis of dementia themselves and are stepping forward to share their experiences of living with

the disease with those who need to hear this voice — practitioners, researchers, policy-makers, and, perhaps most importantly, other people with dementia. DASNI and other emerging networks (e.g., the Scottish Dementia Working Group) are a critical link for researchers wishing to share the results of their work directly with the communities most immediately affected.

Together, these three notions of adaptation, dialogue, and advocacy serve as guiding principles for an emerging model of knowledge translation that can be used to foster self-understanding and self-care among people with early-stage dementia. Further research in this area will provide insight as to the particular strategies that are most effective for making new research knowledge useful and practical for this growing population.

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