

# **THE DEMENTIA SUPPORTIVE ENVIRONMENT FRAMEWORK: IMPLICATIONS FOR RECREATION AND LEISURE**

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## **Background**

According to the Canadian Study of Health and Aging (CSHA, 1994a), one in thirteen Canadians over the age of 65 years has Alzheimer Disease or a related dementia. With the rapidly increasing older adult population, the numbers of persons with dementia in Canada is projected to increase dramatically over the next several decades, rising to over three-quarters of a million Canadians by the year 2031 (CSHA, 1994a). A majority of persons with Alzheimer Disease or a related dementia live in the community and are cared for primarily by family or friends (CSHA, 1994b). The current trends suggest that as the population ages, more and more Canadians with dementia and their caregivers will need some level of formal and/or informal care in their lifetimes (Gillick, 1999).

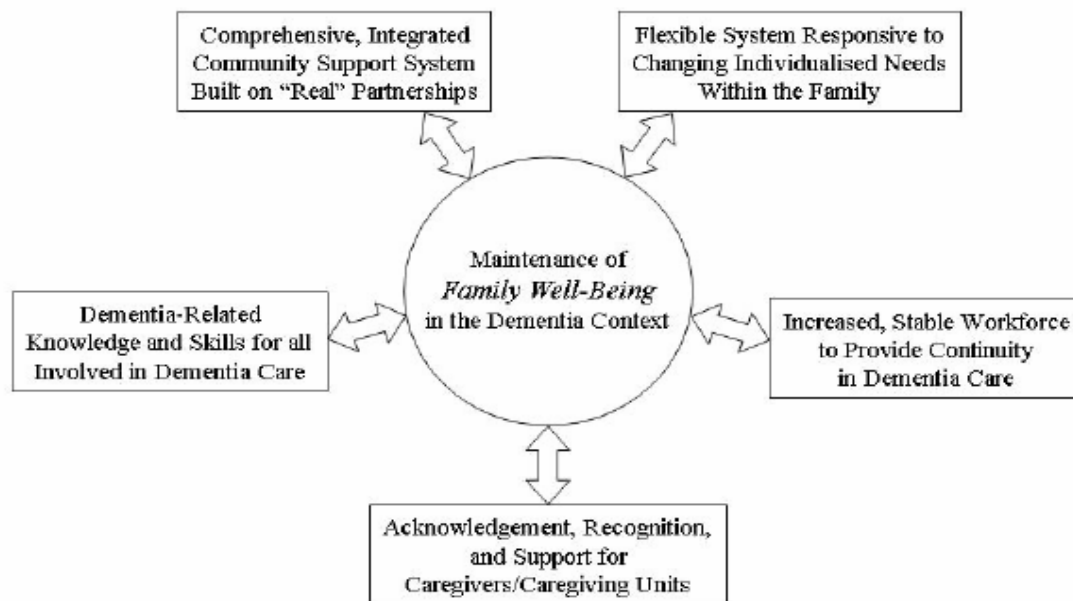
In response to these concerns, the Ontario government initiated the Strategy for Alzheimer Disease and Related Dementias focused on improving the quality of lives of persons living with dementia and their families. The Strategy included a research initiative that sought to identify the needs of and issues faced by community-based caregivers who were caring for persons living with Alzheimer Disease or a related dementia, and in particular, their use and perceptions of formal community support services. The process resulted in the *Dementia Supportive Environment Framework*, an alternative framework for dementia care developed by and for caregivers of persons with dementia and supported by formal care providers, planners, and policy makers (Smale & Dupuis, 2004b). This framework has major implications for researchers, teachers, and practitioners working in recreation and leisure. The purpose of this paper is to describe the Framework and discuss its implications for recreation and leisure.

## **Method**

Guided by the Family Adjustment and Adaptation Response Model (FAAR) (Patterson, 1988), the research process followed three phases. In the first phase, a comprehensive survey was administered to 2,244 community-based caregivers of persons living with dementia across Ontario that gathered detailed information on: (1) the nature of their caregiving careers and the specific activities in which they are engaged; (2) their awareness, use of, and satisfaction with community support services, as well as the constraints they face in accessing them; (3) the impacts of caregiving on them and their families; and (4) what informal resources and capabilities they bring to the demands of caregiving (Smale & Dupuis, 2004a). In the second phase, 14 focus groups were conducted in seven regions across Ontario with a total of 142 caregivers and care providers that explored in depth the most critical issues raised by caregivers in the survey. The focus groups identified four overarching and interconnected themes at the core of their caregiving experiences: (1) system delivery and systemic issues; (2) human resource issues; (3) public awareness and education; and (4) caregiver empowerment and well-being (Dupuis & Smale, 2004). The final phase of the process involved a full-day working focus group comprised of 20 caregivers and 23 care providers, policy makers, decision-makers, and health professionals with the expressed purpose of developing

fundamental principles and specific strategies for change to help overcome the issues and difficulties faced by caregivers. Five key principles centring on systemic issues, human resource issues, and caregiver well-being emerged from this phase and gave rise to the Dementia Supportive Environment Framework – a model for change that better ensures that the needs of persons with dementia and their families are met (Smale & Dupuis, 2004b). A visual representation of the model is presented in Figure 1.

**Figure 1: The Dementia Supportive Environment Framework**



### **The Dementia Supportive Environment Framework and Its Implications for Recreation and Leisure**

The Framework places at its core a foundational principle in support of the maintenance of family well-being in the dementia context. In support of this foundational principle, our interactions with caregivers gave rise to five other key principles that serve as critical components in the Framework that must be incorporated to achieve family well-being. For every principle, the integration of recreation and leisure can play an important role in facilitating the capability of families in the dementia context to sustain their overall well-being. Of necessity in this brief abstract, the inherent richness of each principle can only be partially described.

The foundational principle of the Framework, the maintenance of family well-being in the dementia context, recognises that the primary objective of creating a supportive environment is to support families as caregiving units. Focusing just on the person with dementia or the primary caregiver ignores the fact that the family as a whole is the context of care and is affected by the illness experience (Clarke & Keady, 1996; Davis, 1996; Robinson, 1994). As a daughter caring for her father-in-law emphasised: “I have found by going through this that my husband closes up and it really affects our

home and family life... life isn't the same anymore in our home. No freedom, always a commitment, all of the time. It really has torn our family apart." The goal of health and community support services, including recreation and leisure programmes in the community and in long-term care settings, should be to help the family as a whole to adjust and adapt to the situation, to support them in functioning well, and to assist them in continuing to live in "normalized" ways despite dementia, which shifts the focus from servicing the illness to "getting on with life" (Robinson, 1993). Some leisure literature has focused on strengthening families in the dementia context (e.g., Bollin et al., 1998; Cochran et al., 2001; Crispi & Heitner, 2002; Dupuis & Pedlar, 1995; Neumayer et al., 1998; Voelkl, 1998), but the majority of this work focuses on the caregiving dyad rather than on the entire family system. Highlighting the needs of other family members in the dementia context, Beach (1999) also found that caring for a grandparent can have a significant impact on adolescents and alter their leisure lifestyles.

The first of the five principles identified by caregivers that needs to be addressed before family well-being is achieved involves a comprehensive, integrated community support system built on "real" partnerships. This principle respects multiple and equally valuable knowledge bases needed for quality dementia care and advocates the development of reciprocal, sharing, and collaborative partnerships in care that allow for direct involvement in decision-making by persons living with dementia, family partners in care, and professional care providers (Adams & Clarke, 1999; Robinson, 1994). It demands the inclusion of voices of persons living with dementia and their partners in care in the design and delivery of care (Barnett, 2000; Goldsmith, 1996), and is proactive rather than reactive by anticipating issues and challenges rather than simply responding when crises arise (Zarb & Oliver, 1993). Schleien et al. (1996) found that collaborative programme planning of community leisure services involving staff working closely with families in the design of programmes was the most successful organisational practice leading to inclusive programmes. Recreation professionals can further help by ensuring the fluidity of leisure programmes from the community to long-term care (Flynn Reuss et al., in press).

The second principle focuses on the development of a flexible system responsive to the changing, individualised needs within the family. The dementia experience is context specific and the timing and nature of changes can be difficult to predict (Clarke & Keady, 1996). To meet these ever-changing needs, a continuum of care options is needed in all communities. Some caregiving families are not able to cope well with the changes they face, and hence, need specific resources and supports to deal with those challenges. User-directed services and service delivery options are required that respect the choices of caregiving families and allows them to respond more quickly and effectively to changing demands and needs (Pedlar et al. 1999; Robinson, 1994; Zarb & Oliver, 1993). The importance of having programmes that meet the needs of all families living with dementia, regardless of sexual orientation, ethnic or cultural background, or age of onset also must be recognised (Dieser & Peregoy, 1999). As a daughter caring for her mother emphasised: "Develop programmes that suit each individual caregiver and each individual care receiver's needs. Listen to the specific needs that the caregiver has for his or her care receiver and send a trained respite person who can handle the situation and develop a specific programme for the needs of both parties involved."

The third principle of the framework focuses on the provision of dementia-related knowledge and skills for all involved in dementia care. All those working in dementia care, including the families themselves, need knowledge on various aspects of dementia and the development of skills to be more responsive to the challenges of dementia care. This principle calls for core competencies in dementia care and emphasises the need for educational and professional development opportunities for all partners in dementia care. Leisure and recreation professionals can help educate families by providing them with practical and effective strategies for coping in their caregiving roles. A Changing Melody – a learning and sharing forum specifically designed for persons living with dementia and their partners in care – hosted in Toronto in November 2004 by the Murray Alzheimer Research and Education Programme is an innovative example of how recreation and leisure professionals could partner with other health care professionals to provide a combined learning and leisure experience for the whole family. Smith (2004) cited the importance of recreation and activity staff in long-term care facilities in Ontario, but also noted that many of these staff “have no standard training and are not considered valued members of the multi-disciplinary care team. Their educational training ranges from university degrees in recreation therapy to little or no formal training whatsoever” (p. 22). This scenario is true in community-based programmes as well. There is a need for the identification of core competencies required by all those working in dementia care, including those working in recreation and leisure programmes, and steps put in place to ensure that staff have the knowledge bases and skills required to work with persons living with dementia and their families.

The development of an increased, stable workforce to provide continuity in dementia care is the fourth principle of the framework. This principle recognises that a family’s sense of security and confidence in services is enhanced when there is continuity in care providers (Zarb & Oliver, 1993). This principle values the caring work performed by formal care providers, including those working in recreation and leisure. However, our understanding of the experiences and needs of leisure professionals working with persons with dementia remains limited. Further, educating other members of multidisciplinary teams on the role of leisure in the dementia context can only help improve relationships on those teams in the development of real partnerships in care.

The final principle of the Dementia Supportive Environment Framework involves the provision of acknowledgement, recognition, and support for caregiving families and the contribution they make to dementia care. This principle acknowledges the family as “expert” on the dementia experience and highlights the importance of hearing and understanding families’ knowledge bases and incorporating their voices in decision-making and the creation of care policies (Coates & Boore, 1995; Robinson, 1994). Ways to support their caring roles include provision of financial compensation and the creation of flexible workplace policies for employed caregivers. Further, all members of the family unit will need different supports over the course of the disease to help them deal with the changing circumstances of dementia. Recent research has identified how leisure participation and pleasurable activities (Mannell et al., 2003; Thompson et al., 2002) as well as leisure coping (Smale & Dupuis, 2003) can help family members cope in their caregiving roles. Leisure education, more technological interventions, and alternative philosophies of respite such as viewing respite as an outcome rather than as a programme

also have been cited as important means to increase the coping capacity of caregivers (Argueelles & von Simson, 1999; Carter et al., 1999; Strang, 2001).

Hence, recreation professionals have an opportunity to facilitate the maintenance of well-being among families in the dementia context by developing and integrating meaningful leisure education, programmes, and services in to the Framework. Opportunities for their integration are available in aspects of all of the key principles and recreation professionals should seize these opportunities to help families living in the dementia context.

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