Chapter 19
Teaching and Supporting Clients with Dementia and Their Caregivers in Daily Functioning

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Look, he is happy doing the gardening by himself with these adaptations. Now, I don't feel helpless anymore and I have time to do my own activities.

—A caregiver wife

Abstract Community-based occupational therapy for clients with dementia and their caregivers is a client-centered and family-centered intervention that enables clients with dementia to participate in meaningful activities of daily living (ADL) in their own environment. It enables caregivers to support these clients in ADL and reduce the caregiver's burden. Occupational therapists (OTs) achieve this outcome first by analyzing the life stories and the needs and motivations for meaningful daily activities of these clients and their caregivers in the past and present, second by enabling clients with dementia to do meaningful activities in ways that will enhance their ability to participate by using strategies to compensate for their cognitive decline, and thirdly by modifying the client's environment to better support participation. Caregivers are trained in supervision and problem solving and in using cognitive and behavioral strategies to change their coping behavior and reduce their burden of care.

Keywords Behavioral interventions • Caregiver burden • Dementia • Environmental adaptations • Home modifications.

Definition

Dementia is a chronic and degenerative disease that causes disorders of memory; behavioral problems; and loss of initiative, of independent functioning in daily activities, and of participation in social activities. These problems (1) decrease the well-being of people with dementia and their caregivers (Graff et al., 2007), (2) put pressure on family and friends' relationships (Coen, 1998; Graff et al., 2006a,b; Jepson et al., 1999) and (3) cause high health-care costs.

Community-based occupational therapy for clients with dementia and their caregivers is a *client-and-caregiver-centered intervention.* The intervention enables

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clients to participate in meaningful activities of daily living (ADL) in their present environment and helps caregivers to support these clients with dementia in these activities and reduce their caregiver burden. These definitions follow the World Federation of Occupational Therapists (WFOT, 2004), the Canadian Association of Occupational Therapists (CAOT, 2008), the consensus of guidelines of this community-based occupational-therapy program (Graff et al., 1998, 2000, 2003, 2006b; van Melick et al. 1998, 2000), and the Dutch Foundations of Occupational Therapy (Kuijper et al., 2006).

Development of the Intervention

This client-caregiver–centered intervention (van Melick et al., 1998, 2000) was developed in 1996 to 1998 by a workgroup of occupational-therapy experts in a consensus process (Graff et al., 1998, 2000). Its feasibility was tested (Graff et al., 1998, 2000), and the contents and process of community occupational therapy were identified through a qualitative case-study analysis (Graff et al., 2006b).

Purpose, Rationale, and Objectives

The intervention is directed to *clients* with dementia and their *caregivers*. The focuses are on conducting optimal adaptation of the limitations caused by the dementia clients' cognitive decline. The aims are improvement of problem- solving and coping behavior and maintenance of skills that enable clients to participate in meaningful everyday activities. The aims for the caregivers are to give them support and to facilitate their burden so that they in turn encourage the clients' participation in meaningful ADL. The intervention goals are based on the needs, interests, beliefs, habits, and roles of both clients and caregivers. This intervention approach is based on the model of human occupation (MOHO) (Kielhofner, 2007) and narrative methods (Hasselkus, 1990; Riopel-Smith and Kielhofner, 1998). Here, information originating from clients' and caregivers' stories, beliefs, needs, interests, habits, roles, norms, and goals are interpreted for use in the goal-setting and intervention processes.

Method

Candidates for the Intervention

The intervention is directed at all people with *mild to moderate dementia* (Mini–Mental State Examination [MMSE] score of 10 to 24) (Folstein et al., 1983), who are living

in the community, and at their caregivers (partners, family members, neighbors, or friends) who support them at least one day a week, or at people living in homes for the elderly.

Epidemiology of Dementia and Caregiving

Dementia is one of the three major diseases that make the largest demands on health care (Meerding et al., 1998; Wimo et al., 1998, 2003, 2006), and is a major cause of disability and care burden in the elderly (Jönsson et al., 2006).

The world prevalence of dementia has recently been estimated at 24.3 million people. This is expected to double over the next 20 years (Ferri et al., 2005). In 2002, in the Netherlands, nearly 1% of 65-year-olds suffered from dementia. This percentage rose with increasing age to around 40% in people aged 90 and over. In 2050, it is predicted that 2.2% of 65-year-olds will suffer from dementia. Older people with dementia (age >65 years) are mostly women (80%). Of the younger people with dementia (age <65 years), the mean age is 59 years; here 50% are men and 50% are women (Dutch Health Council, 2002).

In 2003, dementia was responsible for 5.3% of the total health care costs, which was 14% of the age-specific total costs for people aged 75 to 84 and 22% for people aged 85 and older (Sobbe et al., 2006). In 2002, 39% of dementia patients needed continuous care, 38% needed home care daily, 23% needed home care occasionally, and 60% of community- dwelling dementia patients had a need for daily or continuous care.

In the Netherlands, there are 3.73 million caregivers. Most are the partners (70%) or daughters (28%) of people with dementia. About 750,000 people deliver care for more than 8 hours per week and for longer than 3 months, and 150,000 to 200,000 caregivers report a very high burden of care (Raad voor de Volksgezondheid en Zorg, 2006). Therefore, it is important to implement effective and efficient health care interventions that increase the independence and well-being of people living with dementia, decrease caregiver burden, and permit a more efficient use of scarce health care resources (Karlsson et al., 1998).

Settings

Occupational therapy aimed at clients with dementia and their caregivers is conducted at the client's home, in a community-based occupational therapy programs, or in a nursing home (Graff et al., 2006b, 2008; Kenens and Hingstman, 2003). Referrals to occupational therapy are made from outpatient services, memory clinics, hospitals, nursing homes, homes for the elderly, outpatient mental health services, and community health services, and by general practitioners.

The Role of the Occupational Therapist in Applying the Intervention

With this client-caregiver–centered intervention, the caregiver acts as the expert of his own caregiving situation. In such an extensive, interactive, and complicated intervention situations, the OT has different roles for different intervention approaches. The OT has the role of a *supervisor and teacher* when the cognitive and behavioral approach is conducted, and fulfills the role of a *coach* and a c*onsultant* when acting together with the caregivers and the team members.

Results

Clinical Application

Both clients and caregivers are actively involved in this process.

The Diagnostic Phase

This phase is conducted by performing interviews with the dementia client and the caregiver. Narrative techniques are used, such as the Occupational Performance History Interview (OPHI; Kielhofner et al., 1998; Riopel-Smith and Kielhofner, 1998) and the Ethnographic Interview (Hasselkus, 1990). The stories of both the client and the caregiver are analyzed in relation to needs, interests, beliefs, habits, roles, and motivation for meaningful activities. The process is completed with the clients' and the caregivers' expressed desire to choose and prioritize their most important problems in occupational performance. Each one of these interviews is interpreted together with the story of the OT.

The story of the OT is based on the observations of (1) the clients' skills in performing meaningful ADL, (2) caregivers' skills in supporting the clients' performance, and (3) the social and physical environment. This phase cover four sessions.

The Goal-Settings Phase

The goals are stated based on the results of the diagnostic phase and in cooperation with both clients and the OT during one session.

The Intervention Phase

The interventions are tailor-made to each individual client and caregiver's circumstances and adapted to their personal abilities and the actual possibility of adapting the social and physical environment. This phase contains five sessions over 5 weeks.

The following strategies, or combinations of them, are used:

- *The rehabilitation strategy*. The clients perform tasks in natural ways and thus demonstrate their skill levels.
- *The cognitive and behavioral strategy*. During these sessions, caregivers are taught how to cope with the clients' behavior and to solve problems that occur. Moreover, the caregivers are trained to support the clients' meaningful tasks. The aim is to reduce the caregivers' burden of care and to improve caregivers' participation in their own meaningful activities. The caregivers learn about the clients' disease and behavior, technical skills (task simplification and communication skills), problem solving, and home modification skills.
- *The compensation strategy* includes the clients learning how to use strategies, such as verbally rehearsing sequential steps, which compensate for their cognitive decline. For example, the OT teaches a client with dementia how to perform one of the gardening activities by using appropriate strategies such as first saying the steps that will be performed during this activity, accordingly looking around for environmental adaptations and instructions, and listening to verbal cues of the caregiver, and making use of these environmental adaptations, cues, and instructions.
- The OT conducts environmental adaptations, such as simplifications in the environment with the use of visual or hearing memory aids and written sequential task plans.

The Intervention Eases Impairments, Activity Limitations, and Participation Restrictions

The effect of occupational therapy should be based on its quality, that is, on whether or not a goal is reached. For example, if the client is able to perform only one meaningful activity several times a week, this result may improve the client's occupational performance and participation in ADL, and increase his or her and or the caregiver's quality of life, mood, and well-being (Graff et al., 2006b).

Evidence-Based Practice

Outcomes of this client-caregiver–centered intervention are diverse, client-driven, and measured in terms of participation in ADL, competence, or satisfaction derived from participation.

This client-caregiver–centered community occupational therapy program was evaluated in a pilot study that assessed its quality and practical usefulness (Graff et al., 1998, 2000). The caregiver role was identified by describing the process and contents of program (Graff et al., 2006b).

The effectiveness of community-based occupational therapy for older people with dementia and their caregivers (n=135) was effective in improving the

participants' daily functioning (skills and need for assistance), mood and quality of life, and the caregiver's sense of competence (Graff et al., 2006a, 2007). The results were supported by Gitlin et al. (2001, 2005) and by Steultjens et al. (2004).

Moreover, community-based occupational therapy was found to be cost-effective (Slobbe, et al., 2006; Graff et al., 2008) in terms of improvement in clients' skills in daily functioning, a decrease in the need for help, and an increase in the feeling of competence in the caregivers (Graff et al., 2008).

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