Impact of Dementia-derived Nonpharmacological Intervention Procedures on Cognition and Behavior in Older Adults With Intellectual Disabilities: A 3-year Follow-up Study

Luc P. De Vreese*, Ulrico Mantesso†, Elisabeth Weger†, Annachiara C. Marangoni†, and Tiziano Gomiero†

*Department of Primary Care, Psychogeriatric Service, Local Health District of Modena, Modena; and †ANFFAS Trentino Onlus, Trento, Italy

Abstract Dementia appears at a higher rate among some adults with intellectual disabilities (ID) and this potentially poses a greater risk of nursing home admission. Yet, to date, there is no evidence on the efficacy of general dementia-derived environment-, personnel-, and patient-oriented intervention strategies in delaying onset of dementia or in slowing down its rate of progression in this population. To investigate the feasibility and efficacy of a multicomponent nonpharmacological approach, the authors studied a sample of 14 adults with worsening cognition and everyday functioning who were no longer manageable by their family or staff in day centers or group homes, and who were relocated in a model special care unit (SCU) designed to proactively accommodate the needs of people with ID and dementia. Baseline level and rate of decline across a 3-year period were assessed by means of the Dementia Questionnaire for Persons with Intellectual Disabilities and compared to two control groups not in dementia-capable programs matched for age, sex, and severity of ID. After 3 years, the authors found some improvement in cognition and stabilization in everyday functioning and behaviors in the SCU residents and a worsening in the control groups. The authors noted that enrollment in a dementia-capable program facilitated daily practice of residents’ residual skills and abilities, enhancing their memory and verbal communication, that the prosthetic environment contributed to activity maintenance and appropriate intellectual challenges, and that the greater participation on an individual level added to the skill maintenance. Although the interpretation of these positive findings is not straightforward, they confirm the validity of this “in-place progression” model and provide a platform for continuing progress in person-centered services and care for aging persons with ID.

Keywords: dementia, Down syndrome, intellectual disabilities, person-centered, special care units

INTRODUCTION

Some adults with intellectual disabilities (ID), in particular those with Down syndrome (DS), are at an increased risk of dementia (Cooper, 1997; Coppus et al., 2008; Janicki & Dalton, 2000; Strydom, Livingston, King, & Hassiotis, 2007; Strydom et al., 2010; Zigman, Schupf, Devenny, Schubert, & Silverman, 2004). Dementia among adults with DS is presumed to be due to Alzheimer’s disease (AD) (i.e., dementia of the Alzheimer’s type (DAT); Prasher, 2005) and consequent to a long-life overexpression of the amyloid-beta protein precursor, whose gene is on chromosome 21. Also, among adults with other types of ID, DAT appears to be the most prevalent form of progressive dementia (Strydom et al., 2009; Zigman et al., 2004).

Although virtually all adults with DS over the age of 40 have sufficient neuropathology for a histological diagnosis of AD, a small subset of adults with DS never develop the signs and symptoms of DAT, even in the presence of anterograde and retrograde episodic amnesia and executive dysfunctions, thought to be a prodromal (preclinical) phase of DAT (Ball et al., 2004; Holland, Hon, Huppert, Sevens, & Watson, 1998). A similar scenario in the general aging population occurs where some persons function normally despite significant neuropathology (Desai, Grossberg, & Chibnall, 2010; Hulette et al., 1998) or manifest domain-specific (amnesic or non amnesic) or multiple domain deficits without progressing to AD (Petersen, 2004).

In the general population, this discordance between the absence of clinical decline and Alzheimer’s neuropathology has been explained in terms of a reserve capacity hypothesis where there are individual differences in the ability to more efficiently use brain networks or to recruit alternative ones in the presence of a progressively accumulating neuropathology (Stern, 2009; Thal, 2006). Recent in vivo imaging studies suggest molecular, cellular,