A pilot study of a test for visual recognition memory in adults with moderate to severe intellectual disability

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1. Introduction

Persons with intellectual disabilities (ID) have a higher risk of developing Dementia of Alzheimer Type (DAT) compared to the general population. The prevalence rate of DAT in persons with Down Syndrome (DS) was reported as 22.1% for adults age 40 or older and 56.4% for adults age 60 or older (Janicki & Dalton, 2000). The prevalence rate in persons with non-DS etiologies of ID was reported as 4.2% from the age of 65–74 years (Zigman et al., 2004). In contrast, the prevalence rate of DAT in the general population ranges from 1.4% to 1.6% for ages 65–69 years (APA, 2000). The majority of adults with ID can maintain a quality of life with self-care skills and some elementary occupational skills under a high level of supervision. However, these skills deteriorate rapidly with the development of DAT and one-on-one care or nursing care is needed. Since current treatments for DAT focus on slowing the progression, it is of great clinical importance to detect DAT as early as possible.
Memory decline beyond the normal ageing process is known to be the earliest symptom of DAT in the general population. Some studies have reported that persons with ID also exhibit patterns of memory impairment similar to those in the general population (Devenny, Krinsky-McHale, Seren, & Silverman, 2000; Devenny, Zimmeril, Kittler, & Krinsky-McHale, 2002; Krinsky-McHale, Devenny, & Silverman, 2002). Palmer (2006) reported that persons with DAT and ID also revealed deficits consistent with the DSM-IV-TR criteria for DAT which emphasizes deficits in cognitive functioning. In contrast, decline in adaptive functioning and emotion/personality changes rather than memory decline have been reported as early indicators of DAT in adults with ID (Aylward, Burt, Thorpe, Lai, & Dalton, 1997; Ball, Holland, Treppner, Watson, & Huppert, 2008; Cooper & Prasher, 1998; Urv, Zigman, & Silverman, 2003). The diagnostic procedure of DAT for persons with ID in clinic settings also relies heavily on the caretakers’ reports regarding the individual’s functional decline and increased maladaptive behaviors. Burt et al. (2005), however, reported that judgment based on caretakers’ reports produced a higher rate of DAT diagnosis than judgment based on objective testing for adults with ID, particularly for individuals with DS. They recommended a combined approach using interviews and direct assessment of cognitive functioning. The Working Group for the Establishment of Criteria for the Diagnosis of DAT in Individuals with Intellectual Disability under the auspices of the International Association for the Scientific Study of Intellectual Disability (IASSID) and the American Association on Mental Retardation (AAMR) (“Working Group”) recommended that a diagnosis of dementia should be discouraged if observable behavioral changes are not accompanied by evidence of cognitive decline. They also recommended both administration of informant-report scales and direct assessment of cognitive functioning of the individuals with ID (Burt & Aylward, 2000).

It is challenging to directly assess cognitive functioning of individuals with ID because of their life-long severe cognitive impairments. A few studies assessed memory functioning of study participants with ID using objective memory tests, but the selection criteria in these studies often restricted study participants to those who were adequately perform the tests (e.g., Krinsky-McHale et al., 2002). Researchers have attempted to develop tests to measure cognitive abilities in individuals with lower levels of ID, such as moderate to severe ID, however, the majority of these tests have not been successful in avoiding floor effects (Hon, Huppert, Holland, & Wastson, 1999; Kay, Tyrer, & Margallo-Lana, 2003). The Working Group recommended a group of objective cognitive tests to detect and monitor DAT among adults with ID, including the Fuld Object Memory Test and the Test for Severe Impairment (TSI). Despite these being recommended tests, previous work we have done with persons with moderate to severe ID has shown that the Fuld Object Memory Test was too challenging, even for many who did not have DAT. On the other hand, many participants showed a ceiling effect on the TSI, including those with DAT. As a consequence, we were unable to differentiate those participants with DAT from those without using these tests (Pyo, Kripakaran, Curtis, Curtis, & Markwell, 2007).

This experience led us to develop the Picture Recognition Memory Test (PRMT) to assess memory functioning of individuals with ID, specifically targeting persons with moderate to severe ID. Our initial study indicated that the PRMT was easy enough that persons with moderate to severe ID were able to perform it without floor effect (Pyo et al., 2007). The aim of this pilot study with similar participants was to investigate whether those with DAT would score significantly lower than those without DAT on the PRMT. The scores of the PRMT, a modified Fuld Object Memory Test, and the TSI were compared between the participants with DAT and the participants who did not have DAT. Because persons with DS have a significantly higher risk for DAT compared to persons with non-DS etiologies of ID, the PRMT scores were also compared between the two groups to investigate whether they showed different patterns on the PRMT. The results of the previous study revealed that comprehension was an important factor that affects scores on objective cognitive tests. Thus, the effect of language comprehension skills on the PRMT score was examined as well.

2. Methods

2.1. Participants

2.1.1. Participants with DAT with moderate to severe ID

Twenty-six participants with DAT were recruited among individuals who were referred for a dementia evaluation at two local mental health clinics. The inclusion criteria were moderate to severe ID from all causes, age 40 years or older, and a diagnosis of DAT based on the DSM-IV-TR Diagnostic Criteria for DAT (APA, 2000). The determination of premorbid ID was based on IQ scores documented in the participants’ medical records. The dementia evaluation was performed by physicians specialized in developmental disabilities included assessment of medical and family histories, medications, and changes in life style, personality, mood, and cognition as well as physical and neurological examinations. Each had laboratory tests to rule out reversible and/or medical causes of functional/cognitive decline. The participants and their informants underwent a thorough clinical interview. The informants were familiar to the referred persons and provided information regarding the persons’ functional and cognitive declines compared to their previous functioning levels. Environmental stress was ruled out as a possible explanation of the declines. Individuals with significant hearing and/or visual impairment were excluded. Informed consents were obtained from guardians of all participants after the nature of the study was fully explained.

2.1.2. Participants without DAT (“Controls”) with moderate to severe ID

Thirty-three participants were recruited from local residential facilities in the community. Inclusion criteria were moderate to severe ID from all causes, aged 40 years or older and no evidence of declines in adaptive functioning and cognitive functioning based on the facilities’ annual evaluations. The determination of ID was based on IQ scores.
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