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The Adaptive Behaviour Dementia Questionnaire (ABDQ): screening questionnaire for dementia in Alzheimer's disease in adults with Down syndrome

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Abstract

The diagnosis of dementia in Alzheimer's disease remains at times problematic in adults with intellectual disability. The analysis of 5-year consecutive data developed a researched-based clinical screening tool for dementia in Alzheimer's disease in adults with Down syndrome. The Adaptive Behaviour Dementia Questionnaire (ABDQ) is a 15-item questionnaire, which is used to detect change in adaptive behaviour. The scale has good reliability and validity, with an overall accuracy of 92%. It is the first clinical tool designed specifically to screen for dementia in Alzheimer's disease in adults with Down syndrome.

Keywords: Alzheimer's disease; Down syndrome; Dementia; Rating scales, diagnosis

1. Introduction

In 1866 John L. Down became the first person to clinically identify the genetic disorder now known as ''Down syndrome'' (DS) when he published an essay whilst working at an asylum for children with learning disabilities (Down, 1866). Alois Alzheimer, on the 3 November 1906, at the 37th Conference of the

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South-West German Psychiatrists, described the case of a 51-year-old woman who had developed severe memory loss, disorientation, impairment of language, disturbance of thought and disruptive behaviour (Alzheimer, 1907). This description was the first of this particular form of ''presenile dementia'' which later became known as ''Alzheimer's disease'' (AD). Now, almost a century later, a definitive association between the two disorders has been established (Berg, Karlinsky, & Holland, 1993). Older adults with DS are at high risk of developing dementia in Alzheimer's disease (DAD; World Health Organisation [WHO], 1992); with age-specific prevalence rates of 9.4% for the age range 40–49 years, 36.1% for the 50–59 years and 54.5% for the 60–69 years (Prasher, 1995). Such evidence has been produced in the absence of established accurate tests for DAD in persons with intellectual disabilities (ID), where there continues to be a pressing need to find reliable and valid *antemortem* diagnostic measures for DAD.

It is unlikely that one simple test will be found which can accurately and reliably detect DAD in adults with DS. No such measure has been reported for the non-ID population where greater research efforts have already been underway for many more years. In the non-ID population a definite diagnosis of AD can only be made by histopathological examination of brain tissue. Different *antemortem* diagnostic and screening measures have been investigated but all have limited sensitivity and specificity.

There remain greater difficulties in the accurate diagnosis of DAD in adults with DS as compared to diagnosing DAD in the non-ID population. Diagnostic tests and criteria available for the non-ID population are often not directly applicable to people with ID. Such instruments are often based on a mean intelligence quotient (IQ) of 100 and assess intellectual areas of functioning that cannot be reliably measured in people with underlying intellectual impairment. Furthermore, many tests require good communication and dexterity, intact sensory function and good compliance of individuals. They have also been designed to differentiate DAD from ''normal ageing''. Older adults with ID generally do badly on such prerequisites and therefore virtually all of the established tests for the non-ID population have limited value in the ID population.

Adaptive behaviour has been and remains an area of considerable interest in the field of ID. Inadequacies of intelligence (IQ) testing led to the need to test ''global functioning'' of a person with ID. In the past, this was termed ''social incompetence'' (Doll, 1935) but more recently termed ''adaptive behaviour'' (Heber, 1961). Heber defined adaptive behaviour as ''... the effectiveness with which an individual copes with the natural and social demands of his environment''.

More recently adaptive behaviour was defined by the American Association on Mental Deficiency (AAMD) as ''... the effectiveness of the degree with which the individual meets the standards of personal independence and social responsibility expected of his age or cultural group'' (Grossman, 1977). This allows people with ID to be viewed from a wider perspective rather than testing of isolated cognitive functioning. This applies to all individuals with ID but especially to the ageing