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**QUESTION**

**Question:** How reliable is the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID)?

**Patients:** 179 adults with Down’s syndrome and their carers who were identified by contact with clinicians, and via the Leicestershire register of people with intellectual disabilities. Carers who were interested were sent an information sheet and the DSQIID by post, and ascertained whether the person had other carers willing to fill in the questionnaire to assess inter-rater reliability. On returning the questionnaire, carers were sent another copy to assess test-retest reliability.

**Setting:** UK; time period not stated.

**Test:** The DSQIID. This was developed in the first phase of the study using qualitative information gathered from carers of 24 adults aged 48–72 years with Down’s syndrome and dementia. The DSQIID is completed by a carer who has known the individual for some time (ideally at least 6 months), and consisted of 53 items covering areas such as behavioural changes, loss of memory, social withdrawal, confusion, loss of skills, physical and psychological symptoms, sleep disturbances, and sleep abnormalities. Scores are summed to give a maximum of 53, with a greater score indicating greater change in behaviour over time.

**Diagnostic standard:** Clinical diagnosis of dementia by the local clinician according to modified ICD-10 criteria for adults with intellectual disabilities. Only 117 adults were assessed by a clinician; only these participants were included in ROC curve analysis.

**Outcomes:** Sensitivity, specificity, positive likelihood ratio, negative likelihood ratio, inter-rater reliability and test-retest reliability.

**METHODS**

**Design:** Diagnostic cohort study.

**MAIN RESULTS**

Of the 117 adults assessed by clinicians, 49 had dementia (42%) according to modified ICD-10 criteria. Using ROC curve analysis, a cut-off score of 20 or more on the DSQIID for diagnosis of dementia gave a sensitivity of 0.92, and a specificity of 0.97.

Given this cut-off, a positive test result (indicating dementia) was 31 times more likely in people who had dementia than in those without it (positive likelihood ratio = 31). Similarly, a negative test result (no dementia) was 13 times less likely in a person with dementia than a person without dementia (negative likelihood ratio = 0.08). Inter-rater reliability was high (n = 41; intraclass correlation = 0.9) as was test-retest reliability (n = 52; intraclass correlation = 0.95).

**CONCLUSIONS**

A cut-off score of 20 on the DSQIID gives a high sensitivity and specificity when used for adults with Down’s syndrome.

**ABSTRACTED FROM**


**Notes:** Adults in the study with dementia were older than those without dementia (mean age: 56 years vs 44 years; p < 0.001). It is not clear how the DSQIID would perform in people with Down’s syndrome with and without dementia who had been age matched.

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Deb and colleagues, in developing a screening instrument with robust psychometric properties to detect dementia in persons with an intellectual disability, have made an extremely useful contribution to this field. They properly point out that methods used in the general population for this purpose are not appropriate because of floor effects and the difficulties in establishing standard cut-off thresholds for those with an intellectual disability. They suggested that neuropsychological tests are also not appropriate. Hence, as is the case with many other instruments used with this population, an observer-rated survey instrument was deemed more appropriate.

Improved provisions in infant health care have seen a remarkable increase in life expectancy for people with an intellectual disability. For those with Down’s syndrome, life expectancy was reported to be approximately 9 years in 1929 and 57 years in 1989. A corollary of the increasing size of the ageing population with intellectual disability will be increased pressures on resource allocation. Increased life expectancy for people with Down’s syndrome has led to what Prasher has described as “triple jeopardy”. They can experience premature ageing, as they grow older they are susceptible to the neuropathological changes of Alzheimer disease; and by their middle and old age they are susceptible to the death of their ageing parents who have been their primary carers.

The development of a robust screening instrument for the early detection of the onset of dementia in people with an intellectual disability is therefore especially timely. Support agencies will be better informed for their provision of adequate and appropriate services to this growing population. Until we have a sensitive and reliable biological marker for dementia in Alzheimer’s disease, the DSQIID will provide a reliable means to differentiate age-related changes from those associated with dementia.

**COMMENTARY**