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Validation of the German version of the DSQIID in adults with intellectual disabilities

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ABSTRACT

Background: An observer-rated screening questionnaire for dementia for people with intellectual disabilities (ID), DSQIID, was developed in the UK. So far, the German version has not yet been validated in adults with ID.
Aims/Methods: We validated a German version of DSQIID (DSQIID-G) among adults with ID attending a German clinic.
Procedures/Outcomes: DSQIID-G was completed by the caregivers of 104 adults with ID at baseline (T1), 94 at six months (T2) and 83 at 12 months (T3). A Receiver Operating Curve (ROC) was used to determine the total DSQIID-G cutoff score for the best fit between sensitivity and specificity.
Results: Sixteen of the 104 participants at T1 (15%) received a diagnosis of dementia. At T1, the scores among the non-dementia group ranged from 0 to 33 (mean: 6.7; SD: 7.65), and the dementia group ranged from 3 to 43 (mean: 22.12; SD: 11.6). The intergroup difference was statistically significant (W: 158; $p < .001$) (AUC:.89). A total score of 9 provided the best fit between sensitivity (.94) and specificity (.72).
Conclusions and Implications: DSQIID-G total score can discriminate between dementia and non-dementia cases in adults with ID. A lower cutoff score with a higher sensitivity is desirable for a screening instrument.

What this paper adds

This is the first validation study of a German version of the dementia screening questionnaire, "Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID)", for people with intellectual disabilities (DSQIID-G), which presents data on criterion-related validity. A lower cutoff score of 9 than found in the original UK study (20) provided the best fit between sensitivity (.938) and specificity (.716). A cut-off score of 7 provided higher sensitivity (.938) at the expense of lower specificity (.614). A lower cut-off score to allow for relatively more false positive cases than negative is desirable for a screening instrument like DSQIID as the false positive cases could be excluded in the subsequent full and formal clinical assessment and diagnosis of dementia. Therefore, a DSQIID-G cutoff score of 7–10 could be recommended for screening, although we recommend using DSQIID regularly (every three to six months) over time to assess the trend in score change. Ideally, DSQIID should be

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used in the clinic as an aide memoir when clinicians can take the caregivers through each item in the scale and ask for examples and explanations to help make a clinical diagnosis of dementia. The DSQIID-G can discriminate between dementia and non-dementia cases in adults with intellectual disabilities, as shown by the statistically significant difference in the mean DSQIID-G total score between dementia and the non-dementia groups, and an AUC of.89. Therefore, DSQIID-G appears to be a valid screening instrument for use among German-speaking adults with intellectual disabilities. However, DSQIID won't detect cognitive decline until dementia is manifested clinically.

Data Availability

Data will be made available on request.

Statement

During the preparation of this work the authors used ChatGPT Version 3.5 in order to rephrase sentences in "Methods" section that were used in other works within the same scientific project (avoiding self-plagiarism). After using this tool, the authors reviewed and edited the content as needed and take full responsibility for the content of the publication.

1. Introduction

With the increasing life expectancy in the last five decades, people with intellectual disabilities (ID) are exposed to the risk of age-related neurodegenerative disorders, including dementia. The prevalence of dementia is increased in people with ID compared with the general population (Deb et al., 2022a). For instance, Strydom et al. (2007) found an 18.3% prevalence of dementia in persons with ID without Down Syndrome (DS) at the age of 65 or older. Although older people with ID of various aetiologies are at risk of developing dementia, the prevalence of Alzheimer's dementia is particularly high in people with DS. (Strydom et al., 2016). The age of onset of dementia is earlier in people with ID and DS than those without ID (Deb, 2015), with prevalence rates growing rapidly after the age of 40 (Deb et al., 2022a). However, there are difficulties in making an early and accurate diagnosis of dementia in individuals with ID, and the screening instruments, such as the Mini Mental Status Examination that are used in the general population, often show floor effects when used for individuals with ID because of their pre-existing cognitive impairment, the level of which varies depending on the severity of ID (Deb & Braganza, 1999).

There are many similarities and some differences in the clinical manifestation of dementia between individuals with ID and the non-ID general population. Impaired recent memory and confusion in the context of relatively intact distant memory is likely to be an early symptom in individuals with ID who have a mild ID, whereas loss of skills and behaviour changes are likely to be an early feature for those with more severe ID. Many symptoms, including features of 'frontal lobe dysfunction' (e.g. social withdrawal, slowness or diminished initiative) that tend to appear late in the further course of disease in the general population, may appear early in individuals with ID (Deb et al., 2007a). Ideally, individuals with ID should be screened for signs of dementia before age 30/35. A multi-disciplinary approach should be taken to diagnose dementia in individuals with ID using a combination of informant-rated scales and neuropsychological tests in a longitudinal fashion over time (Aylward et al., 1997; Elliott-King et al., 2016).

Both direct neuropsychological tests involving people with ID and observer-rated scales are used to diagnose and screen dementia in ID (Deb et al., 2022a; Zeilinger et al., 2022). However, it is rarely possible to conduct direct neuropsychological tests on people with severe and profound ID (Deb & Braganza, 1999; Aylward et al., 1997; Rösner et al., 2021). The validity of their use among some people with moderate ID may also be questionable (Aylward et al., 1997). One observer-rated screening instrument, the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID), was developed by Deb and colleagues (2007b) in the UK. The items were created through interviews with caregivers of adults with DS who developed dementia, particularly taking into account the early symptoms of dementia (Deb et al., 2007a). DSQIID is easy to use and shows excellent psychometric properties.

DSQIID has been translated into many languages for worldwide use. Validation studies of Italian (Gomiero et al., 2017), Chinese (Li et al., 2015), Japanese (Takenoshita et al., 2020), Taiwanese (Lin et al., 2014), and French (Rebillat et al., 2021) versions have been published showing good psychometric properties. In the USA, the National Task Group (NTG) has adopted and included most of the DSQIID items in their screening questionnaire NTG-Early Detection Screen for Dementia (NTG-EDSD) (Esralew et al., 2018). They have also posted on their website a translated version of DSQIID in many languages, including a German version. A preliminary but not full validation such as criterion-related validity was published of a German version of DSQIID (Kuske et al., 2017). Therefore, we have decided further to evaluate a German version of DSQIID, DSQIID-G and present its psychometric properties in this paper.

2. Methods

2.1. Study design

The study was conducted in an outpatient clinic for people with ID and mental health in a metropolitan area of Germany. Inclusion criteria were (a) age above 40 years for adults with DS or age above 55 for people with an ID without DS or (b) confirmed diagnosis of dementia. Exclusion criteria were (a) profound ID, (b) lack of consent, and (c) severe physical or sensory impairment. The age

requirement was lower for people with DS due to the increased risk of early-onset Alzheimer's dementia and high prevalence rates after the age of 40 in the DS population compared with a higher age in the non-DS ID population (Deb et al., 2022a; Strydom et al., 2007). The diagnosis of dementia was based on ICD-10 criteria and confirmed in multi-professional case conferences involving psychiatrists, neurologists, psychologists and/or special therapists. The diagnosis was based on all available medical and psychiatric assessments, neuropsychological assessment using the scale developed by Burt and Aylward (2000), as well as the past medical history and information about the living and working situation and education. (Rösner et al., 2021). Laboratory diagnostics and brain imaging were conducted if required and authorized by the patient. The multidisciplinary team that made the diagnosis of dementia was unaware of the DSQIID-G score.

The DSQIID was completed by caregivers who knew the person with ID very well and were blind to the result of the case conference. The caregivers received no additional training before the assessment. The DSQIID was completed by caregivers who accompanied patients to the diagnostic appointments. Before the appointment, the patient`s families/living facilities were informed that the accompanying caregivers should be well familiar with the patients to be able to assess behavioural changes over time. The DSQIID was completed at three different time points: baseline (T1), at six months (T2) and 12 months (T3). Fig. 1 contains a detailed description of the recruitment process. By using repeated assessments, we aimed to investigate the development of dementia symptoms over time.

Six participants skipped T2 and participated at T3; eight participants dropped out because the follow-up assessment was not completed within the necessary time interval. This was mostly due to the logistic limitations during the Covid-10 pandemic.

2.2. Ethics approval

We confirm that the current study adhered to the ethical standards established by the relevant national and institutional committees for human experimentation, in accordance with the Helsinki Declaration of 1975 (revised in 2008). Ethical approval was obtained from the ethics committee at the Königin Elisabeth Herzberge Hospital in Berlin on April 5, 2017. Additionally, the study received approval from the ethics committee at Ostfalia University of Applied Sciences in Wolfenbüttel on June 28, 2017 (resolution number 2/2017). Written informed consent for participation was obtained either directly from the participants or their legal guardians. Consent forms and study information were provided in both German and easy-to-use German language versions.

2.3. Study population

The study participants were recruited from the psychiatric outpatient clinic specialising in ID and mental health at Königin Elisabeth Herzberge Hospital in Berlin. The assessments took place between February 2018 and September 2022. DSQIID-G was administered to 104 participants at T1, 94 at T2 and 83 at T3 (see Fig. 1). Out of the 104 participants, 16 (15%) received a dementia diagnosis (see Table 1). We included adults with mild, moderate and severe ID. The mean age was 53.56 years. DS was diagnosed in 40 (38.5%) participants.

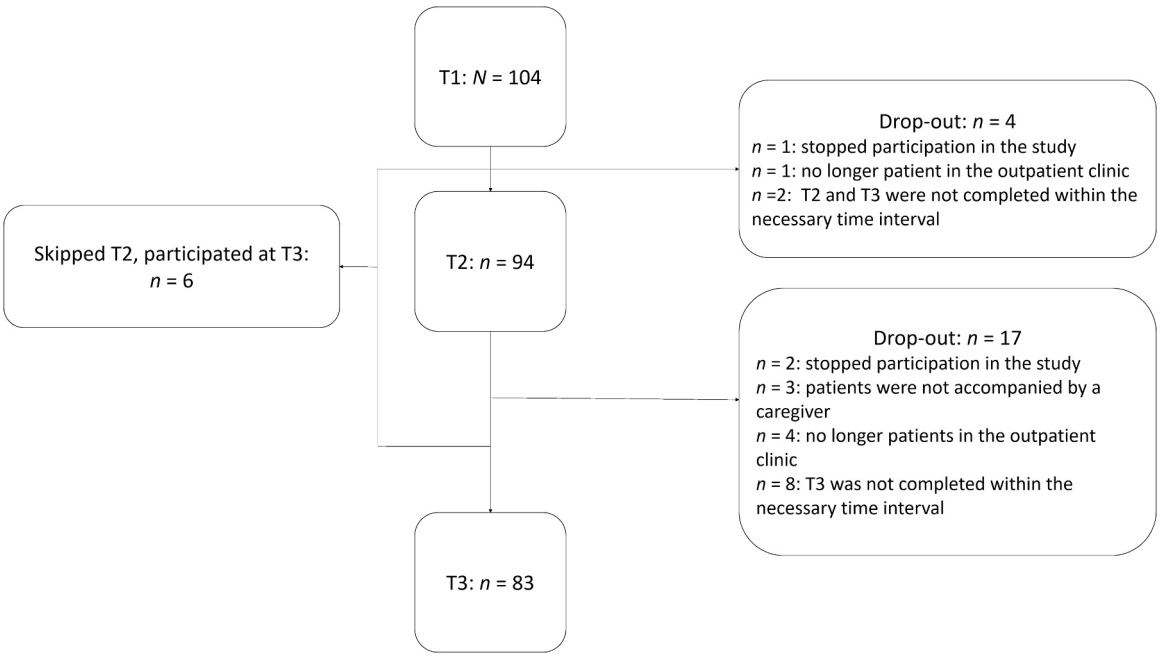

Fig. 1. Recruitment process The number of participants at each assessment: T1 (baseline assessment), T2 (6 months later), T3 (12 months after baseline assessment).

Table 1
Sample characteristics.

	No dementia ($n = 88$)	Dementia ($n = 16$)	*Test statistic*	*p*
Gender (w) *n*, %	43 (49)	11 (69)	OR = 2.28 (95%-CI: 0.66-9.11)	.18
Severity of intellectual disability *n*, %			$\chi^2 = 0.45$ (df = 2)	.80
Mild	20 (23)	3 (19)		
Moderate	47 (53)	10 (62)		
Severe	21 (24)	3 (19)		
F06 (Challenging behavior) *n*, %	21 (24)	6 (38)	OR = 1.90 (95%-CI: 0.50-6.63)	.35
F1 (Addictive disorders) *n*, %	4 (5)	1 (6)	OR = 1.39 (95%-CI: 0.03-15.44)	.57
F2 (schizophrenic disorders) *n*, %	20 (23)	0 (0)	OR = 0 (95%-CI: 0.00-0.99)	**.04**
F3 (affective disorders) *n*, %	51 (58)	2 (13)	OR = 10.5 (95%-CI: 0.01-0.50)	**.001**
F4 (Anxiety, compulsive and trauma disorders) *n*, %	10 (11)	0 (0)	OR = 0 (95%-CI = 0.00-2.45)	.35
F8 (autism spectrum disorders) *n*, %	19 (22)	0 (0)	OR = 0 (95%-CI = 0.00-1.06)	**.04**
Age *Mean (SD)*	53.31 (11.88)	54.94 (5.88)	$W = 0.96$	.64
Psychiatric medication *n*, %	77 (88)	13 (81)	OR = 62 (95%-CI = 0.14-3.94)	.45
Down Syndrome *n*, %	29 (33)	11 (69)	OR = 4.41 (95%-CI: 1.27-17.76)	**.01**

Note. For the exact Fisher's tests, the corresponding odd ratios and 95% confidence intervals (CI) were reported. For the Wilcoxon rank sum test, the W value was reported. For the χ^2 test, the χ^2 value and the degrees of freedom (df) were reported.

As a consequence of applying our study in a clinical setting, most participants were diagnosed with comorbid psychiatric disorders and/or challenging behaviour. Consequently, the rate of schizophrenic or affective disorders was higher compared to the general population. To minimise the influence of comorbid psychiatric disorders on the diagnostic process, it was essential to confirm the diagnosis of dementia in multi-professional case conferences as described prior.

2.4. Assessment instruments: DSQIID

The DSQIID is an informant-based questionnaire that should be completed by caregivers who know the person very well, particularly from before the suspected onset of dementia. The DSQIID consists of three parts. Part one assesses the highest level of functioning ever achieved by the affected person. Part two includes 43 questions regarding dementia symptoms frequent in adults with ID. Each item is evaluated using a four-point scale including the following options: "always has been the case", "always, but worse", "new symptoms," and "does not apply". Responses "always, but worse" and "new symptoms" are coded as "1"; responses "always has been the case" and "does not apply" are coded as "0". Part three includes 10 comparative items (e.g., "Generally appears more forgetful"), possible responses being "yes" (coded as "1") and "no" (coded as "0"). The total score is built as a sum of responses coded as "1" in parts 2 and 3. In the original study, Deb and colleagues (2007) found a total DSQIID score of 20 provided the best fit between sensitivity and specificity for dementia screening. However, it is worth emphasizing that in Deb and colleague's study, a number of participants without a diagnosis of dementia scored above 20 and similarly, a number of participants with a diagnosis of dementia received a score below 20.

2.5. Statistical analysis

We used IBM SPSS Statistics 23 and Rstudio Version 2022.12.0 Build 353 to analyse the data. Participants' demographic characteristics were compared using χ^2 tests, exact Fischer's tests and Wilcoxon- rank sum tests (two-sided, independent samples). Furthermore, we compared the total scores at T1 as well as at T3 using Wilcoxon rank sum tests (one-sided, independent samples). Additionally, we examined if the DSQIID scores changed from T1 to T3 (time frame: 12 months). The group differences between assessment points (T1-T3) were compared using a Wilcoxon rank sum test (one-sided, independent samples). Non-parametric tests were chosen because the data didn't meet the requirements for independent t-tests. An exploratory receiver operating characteristic analysis (ROC) was conducted to examine DSQIID's sensitivity and specificity using different total cut-off scores.

Sensitivity is the percentage of true positives (e.g. 90% sensitivity = 90% of people who will score above a certain DSQIID cut-off score will actually have dementia). Specificity is the percentage of true negatives (e.g. 90% specificity = 90% of people who will score below a certain DSQIID cut-off score will not have dementia).

For selected cut-off scores, Cohen's Kappa values were calculated to measure agreement with the dementia diagnosis secured in the case conferences. Intraclass correlation between T1 and T2 scores was calculated to assess DSQIID's test-retest reliability (time frame: 6 months). Since dementia is a progressive disorder and DSQIID scores were expected to change in the dementia group over time, only participants without dementia were considered in the test-retest reliability analysis. Cases with missing data in relevant variables were excluded from the respective analyses.

3. Results

3.1. Reliability

Test-retest reliability was assessed by using intraclass correlation of DSQIID total scores at T1 and T2 (assessments six months apart) for persons without dementia ($n = 81$). The intraclass correlation (ICC) was 0.68 ($p < .001$; 95%-*CI*:.549 −.785), indicating moderate to good consistency in the ratings.

3.2. Score differences for participants with and without dementia

At T1, the DSQIID was completed in 88 adults without dementia and in 16 persons with dementia. In the non-dementia group, the DSQIID scores ranged from 0 to 33, mean = 6.7, standard deviation (*SD*) = 7.65, and median = 5. In the dementia group, the DSQIID scores ranged from 3 to 43, with mean = 22.12, SD = 11.16, and median = 21.5. The scores were significantly higher in the dementia group (W = 158, $p < .001$).

At T3 (12 months after T1), the DSQIID was completed in 70 adults without dementia and in 13 persons with dementia. In the non-dementia group, the DSQIID scores ranged from 0 to 32, mean = 6.44, SD = 7.33, and median = 4.5. In the dementia group, the DSQIID scores ranged from 7 to 42, mean = 21.46, SD = 10.37, and median = 20. The scores were significantly higher in the dementia group (W = 93, $p < 0.001$).

No significant score changes were observed between T1 and T3. In the dementia group, the average score change was 1 point higher at T3 with an SD of 7.75 points. In the non-dementia group, the average score change at T3 was 0.76 lower, with an SD of 7.21 points.

3.3. Sensitivity and specificity

The ROC analysis was applied for the DSQIID total scores at T1 to evaluate the scale's sensitivity and specificity (Fig. 2). Since we observed no significant change in the DSQIID scores over time (see Section 3.2), we only report the results of the ROC analysis at T1.

We found an area under the curve (AUC) of.89 (95%-*CI*:.81–.97, $p < 0.001$), which indicates good discriminative power. Table 2 shows sensitivities, specificities and Cohen's Kappa values for the cut-off scores 5, 7, 8, 9, 10, 20 and 22. The cut-off scores 5,7,10,20, and 22 were selected based on findings from previous studies (see Table 3); the cut-off scores 8 and 9 were explored additionally. Kappa values varied between 0.185 and 0.483, indicating a slight to moderate degree of agreement between the clinical dementia diagnosis and the DSQIID scores. The best fit between the sensitivity and specificity was found at a DSQIID total cut-off score of 9 (see Table 2). A cutoff score of 7 increased the sensitivity to.938 at the expense of a lowered specificity of.614.

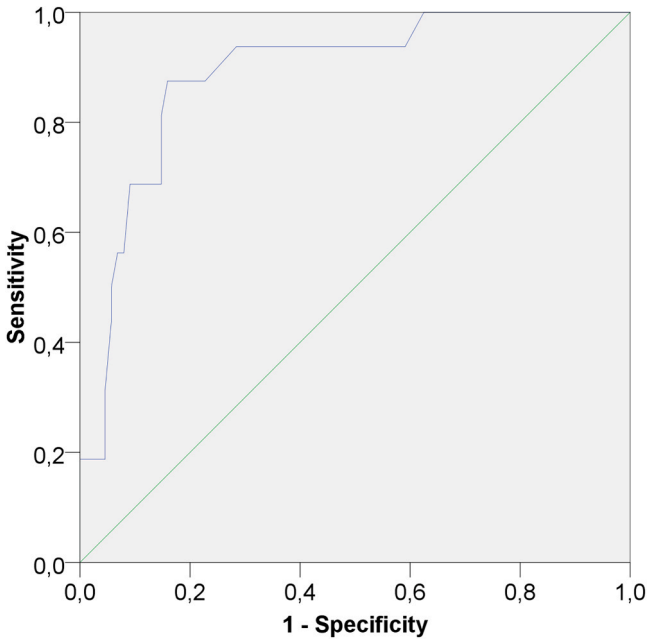

Fig. 2. Sensitivity and specificity analysis for the DSQIID total score at T1 Receiver operating characteristic curve for the Dementia Screening Questionnaire for Individuals with Intellectual Disabilities (DSQIID) at the baseline assessment (T1).

Table 2
Psychometric properties of the DSQIID for different cut-off scores.

	Sensitivity	Specificity	PPV	NPV	Kappa (*p*)
Cutoff = 5	.938	.466	.24	.98	.185 (.002 *)
Cutoff = 7	.938	.614	.31	.98	.299 (<.001 *)
Cut-Off = 8	.938	.693	.36	.98	.379 (<.001 *)
Cut-Off = 9	**.938**	**.716**	**.38**	**.98**	**.405 (<.001 *)**
Cutoff = 10	.875	.773	.41	.97	.444 (<.001 *)
Cutoff = 20	.563	.920	.56	.92	.483 (<.001 *)
Cutoff = 22	.500	.943	.62	.91	.480 (<.001 *)

Table legend: The best-balanced sensitivity/specificity values are marked in bold letters; PPV, positive predictive value; NPV, negative predictive value

Table 3
Recommended DSQIID cut-off scores and sensitivity/specificity values in different studies.

Study	Sample	Language	Cut-Off score	Sensitivity	Specificity
Deb et al. (2007b)	Participants with DS only	English	20	.92	.97
Li et al. (2015)	Participants with ID including DS	Chinese	22	.92	.99
Takenoshita et al. (2020)	Participants with ID including DS	Japanese	10/11	1	.97
Silverman et al. (2021)	Participants with DS only	English	5	.87	.8
Rebillat et al. (2021)	Participants with DS only	French	19	.94	.94
Nübling et al., (unpublished results)	Participants with DS only	German	7	.94	.76
Current study	Participants with ID including DS	**German**	**10**	**.88**	**.77**

Table legend: ID, intellectual disabilities; DS, Down Syndrome

4. Discussion

Although one German scale, Dementia Test for People with Intellectual Disabilities (DTIM), has recently been validated, and the combination of DTIM with a German version of DSQIID has been shown to be more effective than DTIM alone in detecting dementia in people with ID in a German population, the psychometric properties of the German DSQIID have not been assessed previously (Zeilinger et al., 2022; Deb et al., 2022a). This paper presents a more detailed assessment of DSQIID-G, including criterion-related validity and reliability.

Criterion-related validity showed the best fit between an excellent sensitivity (.938) against a moderate specificity (.716) for a total DSQIID-G cut-off score of 9. In the past, different studies found different best-fit cut-off scores (22, 20, 10/11, 10, 7, 5) for sensitivity and specificity because of different study designs (see Table 3). We don't anticipate that the different best-fit cut-off score in our study from the previous studies is due to the translation effect but more to do with the sample selection and definition. Specifically, unlike Deb et al. (2007b) and Li et al. (2015), the current study was analyzing data from a clinic sample. However, our finding is similar to the validation study of the Japanese version of DSQIID, which found that 10/11 is the best fit (sensitivity of 1 and sensitivity of.97; Takenoshita (2020). Another study that used the German version of DSQIID in a population with DS available on the NTG-EDSD site has found the best-fit cut-off score of 7 (a sensitivity of.94 and a specificity of.76), which is close to the findings in this study (Nübling et al., unpublished results). A US study reported even a lower best-fit cut-off score of 5 (a sensitivity of.87 and a specificity of.8) based on the DSQIID items in the NTG-EDSD (Silverman et al., 2021).

Both at T1 and T3 mean DSQIID scores were significantly higher in the dementia group compared with the non-dementia group. This clearly shows that the total DSQIID score could differentiate between dementia and a non-dementia diagnosis. This was also supported by a good value of.89 for the AUC. The score change over 12 months in the dementia group was only slightly higher than that of the non-dementia group. Considering the profound diagnostic procedure employed in this study, the diagnostic assignment is surely confirmed. We suppose that the small score change in the dementia group over the 12-month period may be due to ceiling effects. Once the dementia symptoms have manifested, they may not change much over time unless the scores are compared with the pre-morbid baseline score. Moreover, the DSQIID items are based on dementia symptoms, not on functional impairment. That is another reason why DSQIID must not be used as a diagnostic instrument but as a screening instrument.

It is worth emphasising that DSQIID is a screening instrument, not a diagnostic tool. However, some studies have wrongly used the DSQIID score to diagnose dementia in people with ID and/or DS. As a screening instrument, it is better to use a lower cut-off score, allowing for relatively more false positive cases than false negative cases as the false positive cases will be excluded subsequently through a thorough clinical assessment by experts in the field. Therefore, we recommend a lower score of 7 or 10 for screening purposes than a higher score of 20 or 22.

It is also worth emphasising that DSQIID items were developed using the reporting of early symptoms of dementia by the caregivers of people with ID. Therefore, unlike other instruments, DSQIID does not measure cognitive decline or impairment in adaptive behaviour. Therefore, DSQIID will not detect dementia until the early symptoms are manifested. For the same reason, cognitive decline due to secondary causes like hypothyroidism and depression, etc., are not likely to be detected by DSQIID as they do not necessarily show early symptoms of dementia.

Nonetheless, it should take into account that our study was applied within a clinic sample of people with mental health problems. Therefore, interferences due to symptom overlap (e.g. pseudodementia in depression) may occur, which affect DSQIID scores and analysis. However, this faces clinical reality.

Although the data analyses in the current study are robust and the findings are promising, the readers must be aware of certain limitations. The total number of people with a confirmed diagnosis of dementia is small in the current study. However, apart from Deb and colleagues' original study of DSQIID (2007a), almost all the other studies of the development of diagnostic and screening instruments for dementia in ID included a small number of participants with a confirmed diagnosis of dementia (average less than 20). We tried to address this issue by maximising diagnostic accuracy through multidisciplinary case conferences. Thus, the application of the DSQIID investigated in this study was rather that of a screening tool, and the data have to be interpreted as such. Also, unlike some previous studies, we were able to include participants with severe ID. This shows that the DSQIID can be applied to adults with severe ID. However, we have not provided any separate data specific to this population because of the small numbers. The inclusion criteria of our study set the age limit at 55 years and above for participants without DS. This is an arbitrary cut-off age based on some previous prevalence studies showing an increased prevalence of dementia in people with ID from age 50 onward (e.g. Patel et al., 1993). This may differ from the age limits in other studies, for example, Strydom et al. (2007) included participants aged 60 or older.

Including adults with ID with and without DS is a strength of the current study. However, we believe that the psychometric properties of the DSQIID should be investigated by future research. In particular, we could not report reliability values such as inter-rater reliability, internal consistency or split-half reliability. Furthermore, the test re-test reliability could not be assessed within a gap of an acceptable time scale. Additionally, inter-item correlations should be calculated, and single items should be explored regarding discrimination power. However, as the behaviours of participants without a diagnosis of dementia remained relatively stable between T1 and T2, the level of test re-test reliability was good ($ICC = 0.68$) but could have been excellent had we been able to do the test re-test within a short time period. A quarter to a third of the participants in the non-dementia and non-dementia group showed behaviours that challenge. Although a higher rate was found among the dementia group, there was no statistically significant intergroup difference. This may highlight the fact that behaviours that challenge per se may not necessarily differentiate between dementia and the non-dementia groups (Deb et al., 2007a; Deb, 2015; Deb et al., 2022b).

5. Conclusion

To conclude, the German version of the DSQIID is a valid and reliable instrument for screening of dementia in adults with mild, moderate and severe ID with additional mental health problems with and without DS.

CRediT authorship contribution statement

Peggy Rösner: Writing – review & editing, Data curation. **Tanja Sappok:** Writing – original draft, Validation, Resources, Methodology, Investigation, Formal analysis, Data curation, Conceptualization. **Daria Tarasova:** Writing – original draft, Methodology, Formal analysis. **Shoumitro Deb:** Writing – original draft, Supervision.

Declaration of Competing Interest

None.

Data Availability

Data will be made available on request.

Acknowledgement

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