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ORIGINAL ARTICLE

Use of a Screening Tool for Dementia in a Down Syndrome Specialty Clinic

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ABSTRACT

To study the use of a dementia screening tool in our clinic cohort of adults with Down syndrome. To evaluate the functionality of the NTG-EDSD for Dementia as part of a dementia screening protocol for adults with Down syndrome, we conducted a cohort analysis of patients aged 40 and older followed at the Massachusetts General Hospital Down Syndrome Program, noting any clinical interpretation of dementia or mild cognitive impairment (MCI). From September 2023 to September 2024, 54 NTG-EDSD responses were collected. Of these, 14 patients had a clinical interpretation of dementia and/or MCI, and 40 did not have a clinical interpretation of either. Due to the lack of a defined cutoff for the NTG-EDSD, we evaluated the sensitivity and specificity of the NTG-EDSD across various scoring thresholds: ≥ 30, ≥ 20, ≥ 10, ≥ 5, ≥ 3, ≥ 2, and ≥ 1. Sensitivity decreased, and specificity increased as the threshold score rose. Lower thresholds (e.g., ≥ 1) captured all true positives but at the cost of many false positives, whereas higher thresholds (e.g., ≥ 20) improved specificity and positive predictive value, identifying fewer individuals overall but with greater diagnostic confidence. In a real-world clinical setting, the NTG-EDSD lacks sufficient accuracy as a stand-alone dementia screening tool for adults with Down syndrome but may still be useful for guiding caregiver conversations and identifying the need for further evaluation.

1 | Introduction

Individuals with Down syndrome (DS) face a 95% risk of developing biological evidence of Alzheimer's-type dementia (AD) during their lifetime with a median symptom onset age of 55 (Startin et al. 2019). AD, the most common type of dementia, often develops from an earlier stage known as mild cognitive impairment (MCI) (Krinsky-McHale et al. 2020). MCI involves early memory loss or decline in other cognitive abilities (such as language or visual–spatial skills), but individuals typically retain the ability to perform most daily activities independently (Chang et al. 2025). A diagnosis of AD typically requires a comprehensive cognitive evaluation such as a neuropsychological evaluation or referral to a neurologist or psychiatrist (Krinsky-McHale et al. 2020). However, this process is time consuming, involved, and can take months given wait times of specialty care. As identified by the most recent evidence-based clinical practice guidelines for DS, "There is a critical need for practical, standardized and validated assessment tools for use in the clinic to diagnose and stage Alzheimer's disease in individuals with

Abbreviation: MGH DSP, Massachusetts General Hospital Down Syndrome Program.

DS across a spectrum of baseline intellectual abilities" (Tsou et al. 2020).

In response to this new recommendation, the Massachusetts General Hospital Down Syndrome Program (MGH DSP) launched a quality improvement initiative to evaluate the implementation of a newly established dementia screening protocol for patients with DS aged 40 and older. We identified four validated screening tools for AD in DS, each with strengths, limitations, and varied published use in individuals with DS (Esbensen et al. 2017). Screens for dementia include the following: The National Task Group on Intellectual Disabilities and Dementia Practices (NTG) developed the NTG-Early Detection Screen for Dementia (NTG-EDSD) (Silverman et al. 2021), the Adaptive Behavior Dementia Questionnaire (ABDQ) (Prasher et al. 2004), the Dementia Questionnaire for People with Learning Disabilities (DLD) (Evenhuis 1990), and the American Association on Mental Deficiency Adaptive Behavior Scale (AAMD), Part I (Suess et al. 1981).

As previously published, we used the ABDQ and a modified version of the survey in 2022 to screen for dementia in adults with DS aged 40 and above within the MGH DSP (Oreskovic et al. 2025). However, neither version adequately screened for patients with cognitive impairment and/or dementia within the population (Oreskovic et al. 2025). This prompted our search for an alternative screening tool that would be freely available, brief, and able to be completed by caregivers.

The NTG-EDSD was selected because it met all of these criteria and showed promise for integration into routine clinical care. In contrast, the AAMD is significantly longer and more time-intensive, while the DLD requires repeated use over time to detect change, making both less practical for our clinic's screening goals.

We thus began this current study with several aims, to (1) describe our experience selecting an alternative screening instrument for AD in DS, (2) highlight our experience using that instrument, and (3) summarize the scoring results. Given the recommendation that all adults with DS age 40 and older be screened for AD, this study provides useful guidance for clinicians caring for individuals with DS in beginning to implement the recommended guideline (Tsou et al. 2020). Screening for early onset decline could help identify adults with DS who need further diagnostic evaluation for AD.

2 | Methods

2.1 | Setting

The MGH DSP is a multidisciplinary specialty program for individuals with DS. Clinical visits include a physician, a social worker, a nutritionist, a self-advocate with DS, and a program coordinator. In addition to the clinical visit, patients may be referred for visits with the affiliated psychiatrist or neuropsychologists. Wait times for psychiatry and neuropsychological outpatient evaluations can be lengthy for adults with DS in the US, especially in states without a designated DS program, with families waiting up to 12 months or more for an appointment. Prior to a visit, caregivers receive an electronic intake form via email, which they complete with caregiver-reported medical history.

2.2 | Selecting a Screening Instrument

As previously published, and based on the limitations with the use of the ABDQ (Oreskovic et al. 2025), we considered the remaining three caregiver-completed screening instruments: the NTG-EDSD, the DLD, and the AAMD. The National Task Group on Intellectual Disabilities and Dementia Practices' Early Detection and Screening for Dementia (NTG-EDSD), the Dementia Questionnaire for People with Learning Disabilities (DLD), and the American Association on Mental Deficiency Adaptive Behavior Scale (AAMD).

Our ideal screening instrument would, (1) have been previously shown to be valid for use in assessing for AD in DS, (2) be able to be completed independently by caregivers or families, (3) be able to be completed quickly (< 10–15 min) during a clinic visit, (4) yield an actionable result (e.g., a score with established criteria) to guide clinical management, and (5) yield an outcome that can provide immediate clinical care decision support (i.e., completion in a single assessment that does not require longitudinal data or serial assessments over time). Initially, our impression was that the ABDQ best matched these criteria but found that it did not have ideal sensitivity and specificity to screen for AD in our clinic cohort of adults with DS.

Initially, we eliminated the NTG-EDSD due to length, expected completion time, and lack of score with established criteria. However, after excluding the ABDQ as a clinical screening tool, we selected the NTG-EDSD for use in our clinical screening protocol. It was recommended in the adult evidence-based care guidelines and has been anecdotally used by other researchers and clinicians in the DS community (Tsou et al. 2020). We also found that caregivers could complete it quickly within our clinic workflow. In addition to screening for dementia, the NTG-EDSD has also been useful for assessing MCI in adults with DS (Silverman et al. 2021).

The NTG-EDSD is a 63-question assessment designed to evaluate clinical onset of AD through comparison of a patient's behavior at the time of assessment to baseline. Baseline is defined as a patient's behavior prior to any onset of any signs of dementia. The survey is completed by a caregiver and/or parent who knows the patient well. The NTG-EDSD includes eight subsections including: "Activities of Daily Living," "Language & Communication," "Sleep-Wake Change Patterns," "Ambulation," "Memory," "Behavior and Affect," "Adult's Self-Reported Problems," and "Notable Significant Changes Observed by Others." Notably, the "Adult's Self-Reported Problems" section has 6 questions designed to be reported by the patient. The NTG-EDSD is completed using a scale with the following columns: (A) Always been the case, (B) Always but worse in the past year, (C) New symptom in the past year, and (D) Does not apply. The caregiver marks off the column that most accurately answers each question. The NTG-EDSD does not have a standardized scoring cutoff; rather, it is intended to track symptom trends over time and the progression of cognitive changes (NTG-EDSD

Screening Tool 2025). As such, the sensitivity and specificity for this screener has not yet been analyzed for people with intellectual disabilities.

2.3 | Procedure

The NTG-EDSD was self-administered by a caregiver via paper questionnaire during the patient's clinical visit. Questionnaires were completed by the caregivers with a team member available to answer questions. Caregivers completed the NTG-EDSD in the waiting room while waiting for the physician in the exam room, or between sessions with our multidisciplinary clinicians; caregivers were not directly monitored or observed in questionnaire completion. As it is possible that caregivers could have answered the "Adult's Self-Reported Problems" section intended for adults with DS, we chose to focus only on the caregiver report items in this study. Following completion of the questionnaires, responses were scanned and entered into a database for analysis.

In the absence of a standardized scoring guide or cutoff for a positive screen, we analyzed our data using a point system similar to that of Silverman et al. (2021). One point was assigned for each response marked in columns B and C, which indicate the emergence of potential new symptoms of dementia. No points were assigned for responses marked in columns A and D, which indicate an absence of dementia-related concerns. Summing these assigned values, each patient was given a corresponding NTG-EDSD score.

To compare NTG-EDSD scores with clinical interpretations, we reviewed patients' electronic health records (EHR) for clinical interpretation of dementia (D) or early signs of dementia, MCI, henceforth referred to as D/MCI. Patients were recorded as having D/MCI if dementia and/or MCI were explicitly mentioned in any visit notes or documentation elsewhere in the medical chart, including neuropsychological evaluation reports. Patients were recorded as D/MCI absent if there was no explicit mention of dementia and/or MCI in the EHR. Demographic data about the patients were also retrieved from the EHR.

Since the NTG-EDSD does not have an established threshold score for determining a positive screen, we next examined the impact of applying different thresholds (≥ 30, ≥ 20, ≥ 10, ≥ 5, ≥ 3, ≥ 2, and ≥ 1) selected by our team. To assess the clinical utility of the NTG-EDSD as a dementia screening tool, we constructed 2×2 tables for each threshold, comparing the classification based on these raw scores to D/MCI status. Sensitivity and specificity were then calculated for each threshold to evaluate the tool's accuracy in distinguishing between individuals with and without cognitive impairment.

Additionally, we tabulated the combined data from the "Language & Communication" and "Memory" domains of the NTG-EDSD to compare with the findings of Silverman et al. (2021) paper, which found these two domains more sensitive to cognitive decline (Silverman et al. 2021). To assess the clinical utility of the combined "Language & Communication" and "Memory" sections as a dementia screening tool, we constructed 2×2 tables for threshold scores of ≥ 1 and ≥ 2, comparing the classification based on these scores to D/MCI status. Sensitivity and specificity were then calculated for each threshold.

This quality improvement study was approved by Mass General Brigham's institutional review board as part of a quality improvement initiative within the MGH DSP. Data are presented in an aggregate, de-identified manner and was collected to study this quality improvement protocol.

3 | Results

From September 2023 to September 2024, we collected 54 total NTG-EDSD responses from 54 MGH DSP patients aged 40 and older. In our cohort, 31 participants were male and 23 were female. Most (50) individuals with DS were self-identified as White, but 1 was Hispanic, and 1 was Black or African American (Table 1). Among the 54 total responses, the mean NTG-EDSD score was 6.6, with a range of 0 to 40. On clinical chart review, of the 54 screens, 40 were classified as D/MCI absent.

In evaluating the use of different NTG-EDSD threshold scores (≥ 30, ≥ 20, ≥ 10, ≥ 5, ≥ 3, ≥ 2, and ≥ 1) on sensitivity and specificity of screening for dementia and MCI, we found that sensitivity and specificity values were impacted based on the threshold score used. At a threshold of ≥ 30 indicating a positive screen, four participants screened positive, all with D/MCI; 10 participants with D/MCI screened negative. Lowering the threshold to ≥ 20 to indicate a positive screen increased the number of positive screens to 6, capturing 6 of the 14 D/MCI cases while adding 1 false positive. At a threshold of ≥ 10, 11 participants screened positive, 6 of which were with D/MCI and 5 of which were without D/MCI. Lowering the threshold to ≥ 5 resulted in 18 positive screens, identifying 8 of the 14 D/MCI cases but also including 10 false positives. Further decreasing the threshold to ≥ 3 increased the number of positive screens to 26, capturing 9 of the 14 D/MCI cases but also identifying 17 false positives. At a threshold score of ≥ 1, 37 participants screened positive, capturing all of the D/MCI cases. However, this threshold also resulted in 23 false positives. In contrast, at a threshold score of ≥ 2, the number of false positive screens decreased to 20 but only identified 11 of the 14 D/MCI cases (Supporting Information). We summarized the sensitivity and specificity values using these NTG-EDSD threshold scores (Table 2).

To better understand how different sections of the NTG-EDSD may be more informative for distinguishing between cognitively stable adults and those with early clinical progression of AD, classified as MCI, we compared our findings with the findings of Silverman et al. (2021). Silverman et al. (2021) highlighted that the "Memory" and "Language & Communication" domains combined were particularly informative (Silverman et al. 2021). At a threshold of ≥ 2 indicating a positive screen, 14 participants screened positive, 7 of which with D/MCI and 7 without D/MCI; 7 participants with D/MCI screened negative. Lowering the threshold to ≥ 1 to indicate a positive screen, increased the number of positive screens to 22, capturing 10 of the 14 D/MCI cases while adding 5 false positives (Supporting Information). Our analysis showed that using only these two domains with threshold scores of ≥ 1 and ≥ 2 yielded sensitivities of 0.71 and 0.50, respectively (Table 3).

TABLE 1 | Demographic traits of 54 individuals with Down syndrome who had the caregiver-administered National Test Group on Intellectual Disabilities and Dementia Practices Early Detection Screen for Dementia (NTG-EDSD) completed.

	Modified NTG-EDSD Sept. 2023–Sept. 2024 ($N = 54$)
	N (%)
Sex	
Male	31 (57.4)
Female	23 (42.6)
Race	
White	50 (92.6)
Black or African American	1 (1.9)
Other	1 (1.9)
Unavailable	2 (3.7)
Ethnicity	
Hispanic	1 (1.9)
Not Hispanic	53 (98.1)
Age	
40–44	16 (29.6)
45–49	13 (24.1)
50–54	12 (22.2)
55–59	9 (16.7)
60–64	3 (5.6)
65–70	1 (1.9)
Premorbid function/level of ID	
Mild	11 (20.4)
Moderate	29 (53.7)
Severe	5 (9.3)
Profound	1 (1.9)
Unknown	8 (14.8)

To identify which symptoms were leading individuals to screen positive, among the 54 NTG-EDSD responses, we examined the frequency of symptoms reported as either "Always but worse in the past year" or "New symptom in the past year" across all domains. Individuals with DS had new or worsening symptoms in behavior and affect (97), memory (59), notable significant changes by others (46), activities of daily living (43), sleep–wake change patterns (30), and ambulation (24). The most frequently reported changes included difficulties in conversation, with 12 participants appearing to get lost mid-conversation. Other commonly observed symptoms included weight changes (11), obsessive or repetitive behaviors (10), inattentiveness (11), difficulty following simple instructions (11), and losing or misplacing objects (10).

Additional notable symptoms reported by at least eight participant caregivers included problems with learning new tasks or new names (8), not finding words (8), anxiety or nervousness (9), losing track of time (9), and difficulty walking over uneven surfaces (10). A range of cognitive, behavioral, and functional changes was observed, with varying frequencies, including verbal and physical aggression, unsteady gait, changes in personality, and sleep disturbances.

4 | Discussion

The most recent clinical guidelines for DS highlight a critical need for standardized tools to diagnose and stage Alzheimer's disease (AD) in individuals with DS (Tsou et al. 2020). In response, the Massachusetts General Hospital Down Syndrome Program launched a protocol to evaluate dementia screening tools for patients aged 40 and older. Though several dementia screens have been validated in research populations, there is limited data to guide clinicians on the clinical applicability of using a dementia screener in a clinical setting. After previously testing and finding the ABDQ tool ineffective for dementia screening in a clinical setting (Oreskovic et al. 2025), we next piloted the NTG-EDSD as a dementia screening tool. We collected 54 NTG-EDSD responses from 54 patients in the Massachusetts General Hospital, noting a mean score of 6.6. Given the absence of a defined cutoff score for the NTG-EDSD, we explored various threshold scores to identify the 14 participants with D/MCI and the 40 participants without D/MCI. Our findings, including the

TABLE 2 | Comparing sensitivity and specificity values of threshold scores on the National Test Group on Intellectual Disabilities and Dementia Practices Early Detection Screen for Dementia (NTG-EDSD) for $N = 54$ patients September 2023 to September 2024.

Threshold score	Sens	Spec	PPV	NPV	LR+	LR−	DOR
1	1	0.43	0.38	1	1.74	0	—
2	0.79	0.50	0.35	0.87	1.57	0.43	3.67
3	0.64	0.58	0.35	0.82	1.51	0.62	2.44
5	0.57	0.75	0.44	0.83	2.29	0.57	4.00
10	0.43	0.88	0.55	0.81	3.43	0.65	5.25
20	0.43	0.98	0.86	0.83	17.14	0.59	29.25
30	0.29	1	1	0.80	—	0.71	—

Abbreviations: DOR, diagnostic odds ratio; LR, likelihood ratio; NPV, negative predictive value; PPV, positive predictive value; Sens, sensitivity; Spec, specificity.

TABLE 3 | Comparing sensitivity and specificity values of threshold scores on the National Test Group on Intellectual Disabilities and Dementia Practices Early Detection Screen for Dementia (NTG-EDSD) for only the "Language & Communication" and "Memory" sections for $N = 54$ patients September 2023 to September 2024.

Threshold score	Sens	Spec	PPV	NPV	LR+	LR−	DOR
1	0.71	0.70	0.45	0.88	2.38	0.41	5.83
2	0.50	0.83	0.50	0.83	2.86	0.61	4.71

Abbreviations: DOR, diagnostic odds ratio; LR, likelihood ratio; NPV, negative predictive value; PPV, positive predictive value; Sens, sensitivity; Spec, specificity.

sensitivity and specificity observed at different score thresholds, contribute to the growing body of literature, including the work by Silverman et al. (2021), aimed at understanding the effectiveness of the NTG-EDSD in the early detection of cognitive decline in this high-risk population (Silverman et al. 2021). Importantly, our study reports on the clinical utility of using the NTG-EDSD to screen for early cognitive decline in individuals with DS in a routine clinical setting.

Selecting an optimal threshold score involves balancing sensitivity and specificity. Our analysis explored a range of threshold scores, with a score of ≥ 5 yielding a sensitivity of 0.57 and a specificity of 0.75. While this threshold aligns with findings from Silverman et al. (2021)—who reported a sensitivity of 0.87 and specificity of 0.80 for dementia at the same cutoff—it did not demonstrate adequate sensitivity in our sample. As a result, we cannot conclude that a threshold score of ≥ 5, or any other specific cutoff, is optimal for screening purposes.

Additionally, prior work by Silverman et al. (2021) identified the "Memory" and "Language & Communication" domains as especially useful in distinguishing early decline (Silverman et al. 2021). Using a criterion of one or more concerns in these domains, they reported a sensitivity of 0.806 and a specificity of 0.802 for distinguishing between cognitively stable adults and those with D/MCI (Silverman et al. 2021). Our analysis showed that using only these two domains with threshold scores of ≥ 1 and ≥ 2 yielded limited screening accuracy, with sensitivities of 0.71 and 0.50, respectively.

Notably, clinicians and families in our setting reported that incorporating the NTG-EDSD into routine visits added meaningful structure to conversations about cognitive and behavioral changes. The most frequently reported new or worsening symptoms were in "Behavior and Affect," "Memory," and "Notable Significant Changes Recognized by Others." Frequently observed difficulties included getting lost mid-conversation, weight changes, obsessive or repetitive behaviors, inattentiveness, and difficulty following simple instructions. Additional symptoms reported by at least 10 participants included losing track of time, anxiety, and difficulty walking on uneven surfaces. A wide range of cognitive, behavioral, and functional changes were noted, highlighting the varied presentation of decline in adults with DS.

Given the NTG-EDSD is recommended for tracking cognitive changes over time, yet lacks definitive scoring threshold scores, our study provides valuable preliminary insights into potential thresholds for clinical use. We believe this information will be particularly useful for other clinicians seeking to understand how different NTG-EDSD total scores might align with the identification of individuals with dementia. These results demonstrate how different threshold scores influence the number of positive screens and their alignment with clinical interpretations as shown in Figure 1. Higher thresholds identified fewer positive cases while maintaining a lower number of false positives, whereas lower thresholds captured more D/MCI cases but also resulted in more false positives. These findings can inform clinicians seeking to incorporate the NTG-EDSD into practice and contribute to ongoing efforts to refine and validate scoring guidelines for dementia screening in adults with DS. Further research across diverse clinical settings is needed to confirm appropriate and clinically meaningful threshold scores for different stages of cognitive decline.

As illustrated in Figure 1, NTG scores generally increase across the three diagnostic categories: those with no dementia and/or MCI, those with MCI, and those with dementia. This trend suggests that NTG scores may have value in differentiating individuals by cognitive status in clinical and research settings. In practice, this differentiation can aid in early detection efforts, reinforcing the importance of routine screening. However, an open question remains: how do NTG scores correlate with other biomarkers of cognitive decline, such as brain imaging findings? The field is currently seeking the best way to screen individuals, balancing clinical evaluations, caregiver reports, and potential biological markers. Understanding how tools like the NTG-EDSD fit into this broader diagnostic landscape is critical for refining best practices in dementia screening for adults with DS.

Despite the presented threshold scores, outliers were evident in our data. As shown in Figure 1, most participants classified with MCI exhibited lower total NTG-EDSD scores, while those documented with dementia tended to have higher scores. However, individual variation was significant. Among the five individuals documented with only MCI, NTG scores ranged from 1 to 3 (1, 1, 1, 2, 3), indicating that detecting this group may require lower score thresholds. Conversely, the nine participants documented with dementia generally had higher NTG raw scores (2, 5, 7, 26, 26, 34, 34, 35, 35), though three had raw scores below 10. The individual with a score of 2, despite a clinical interpretation of dementia, represents an outlier, as most tested threshold scores would likely have failed to identify this case. These findings emphasize that while NTG screening thresholds should not be used in isolation. Instead, they should complement other clinical assessments, given the ongoing uncertainty regarding the best approach to dementia screening in adults with DS.

Several limitations should be considered when interpreting the findings of this study. Firstly, our data were collected from

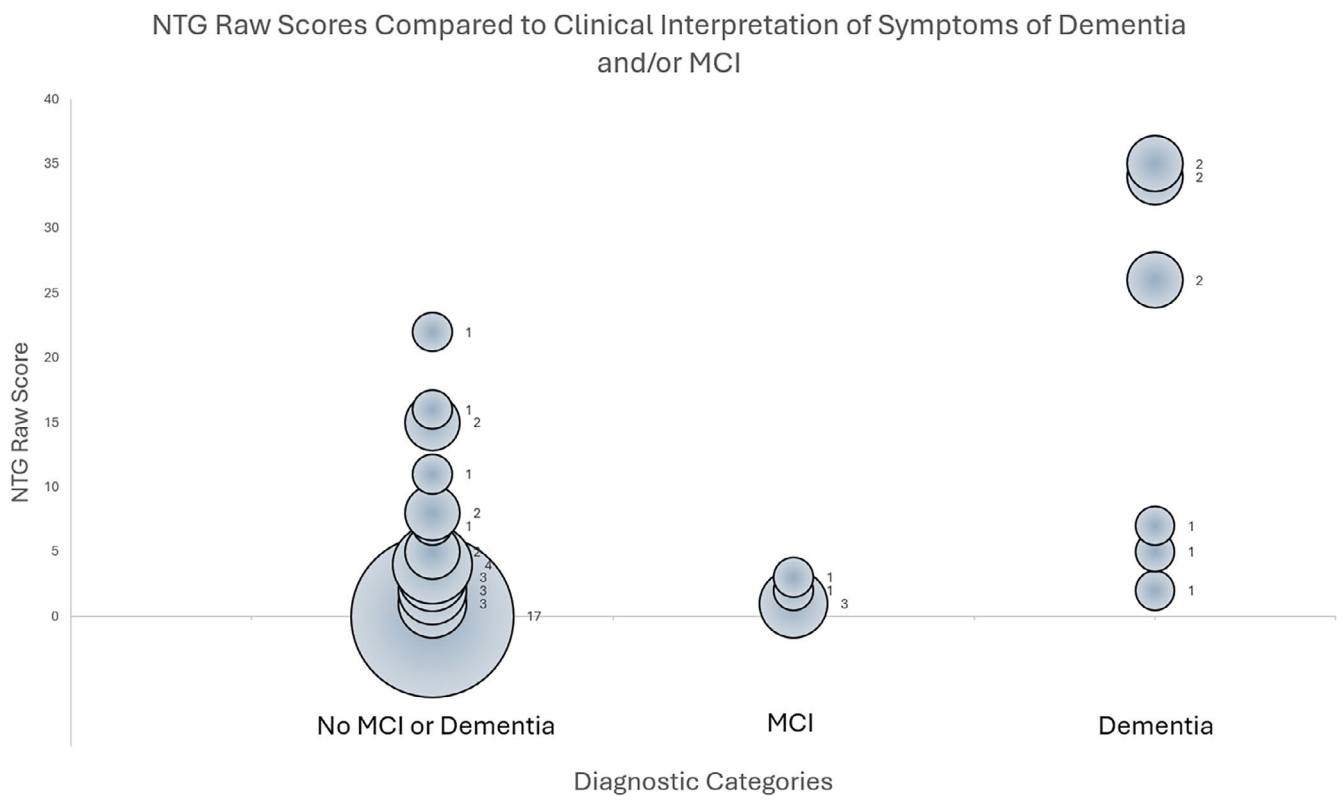

FIGURE 1 | Caregiver-reported National Test Group on Intellectual Disabilities and Dementia Practices Early Detection Screen for Dementia (NTG-EDSD) raw scores of $N = 54$ patients September 2023 to September 2024 compared to clinical interpretation of symptoms of dementia (D) and/or mild cognitive impairment (MCI). Each bubble represents an individual raw score reported by a caregiver of an adult with Down syndrome, with the size of the bubble corresponding to the number of caregivers who reported that same score.

a single clinic cohort, which may limit the generalizability of our results to other populations of adults with DS. While our sample included 54 patients, this is smaller than the sample of 185 adults with DS evaluated in the study by Silverman et al. (2021) across multiple sites. Secondly, a key limitation of this study is that we did not conduct prospective, standardized neuropsychological assessments following NTG-EDSD screening. Instead, we relied on past medical records to determine MCI and dementia status. This approach introduces uncertainty, as the absence of a documented dementia diagnosis does not confirm its absence at the time of screening. As a result, some individuals who screened positive may have had undiagnosed dementia, potentially underestimating the screener's true accuracy.

Additionally, the screeners were completed by caregivers, who could have varying relationships with the individual with DS and different perspectives, potentially influencing their observations and the reported concerns. As a result, the reported score may be influenced by the perspective of the person completing the form or other unmeasured variables. Further research might test the repeat reliability for NTG-EDSD. Lastly, all participants in our study were given a paper copy of the questionnaire at their visit. While this ensured accessibility and ease of use in the clinic setting, it may present challenges in data collection and analysis compared to electronic administration, potentially introducing manual data entry errors and limiting the possibility for automated scoring and analysis.

For future use, researchers and practitioners should consider tracking the duration and nature of the relationship between caregivers and individuals with DS, as these factors may potentially influence the reporting of dementia-related concerns on screening instruments like the NTG-EDSD. Moving forward, it is crucial that future researchers continue to evaluate the utility of other available screening instruments for dementia in adults with DS to ensure the implementation of robust and effective screening practices in this population. This aligns with Silverman et al. (2021) conclusion that NTG-EDSD findings need to be supplemented by additional sources of relevant information to achieve an acceptable level of diagnostic/screening accuracy. Given the ongoing uncertainty surrounding the optimal approach to dementia screening in adults with DS, comparative studies of different screening tools are essential for advancing clinical practice.

5 | Conclusion

Building upon our team's ongoing efforts to develop an effective dementia screening protocol for adults with DS, this study evaluated the real-world clinical utility of the NTG-EDSD. Our findings suggest that the NTG-EDSD scoring system does not demonstrate sufficient accuracy to serve as a reliable standalone screening tool in a general clinical population. However, it holds value as a practical conversation starter, prompting further exploration and discussion with caregivers. These results

highlight the continued need for the development of more robust and clinically useful screening tools tailored to the DS population to better support early detection and intervention for Alzheimer's disease in the DS population, thereby improving long-term outcomes and support.

Disclosure

Dr. Santoro has received research funding from LuMind IDSC Down Syndrome Foundation to conduct clinical trials for people with DS within the past 2 years. She serves in a non-paid capacity on the Medical and Scientific Advisory Council of the Massachusetts Down Syndrome Congress, the Board of Directors of the Down Syndrome Medical Interest Group (DSMIG-USA), and the Executive Committee of the American Academy of Pediatrics Council on Genetics. Dr. Skotko occasionally consults on the topic of DS through Gerson Lehrman Group. He receives remuneration from DS non-profit organizations for speaking engagements and associated travel expenses. Within the past 2 years, he has received research funding from AC Immune and LuMind IDSC Down Syndrome Foundation to conduct clinical trials for people with DS. Dr. Skotko is occasionally asked to serve as an expert witness for legal cases where DS is discussed. Dr. Skotko serves in a non-paid capacity on the Honorary Board of Directors for the Massachusetts Down Syndrome Congress and the Professional Advisory Committee for the National Center for Prenatal and Postnatal Down Syndrome Resources. He has a sister with DS.

Ethics Statement

This questionnaire and retrospective study were approved by the Massachusetts General Hospital institutional review board (IRB protocol: 2020P003890). The study was conducted in accordance with the principles of the Declaration of Helsinki.

Consent

Informed consent was obtained from all patients or their families/legal guardians.

Conflicts of Interest

The authors declare no conflicts of interest.

Data Availability Statement

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section. **Data S1:** Supporting Information.