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ORIGINAL ARTICLE

Implementing a Quality Improvement Initiative to Screen for Dementia in a Down Syndrome Specialty Clinic

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ABSTRACT

Using quality improvement methods, we aimed to implement a protocol to assess for dementia among adults with Down syndrome (DS). To track implementation, interval retrospective chart review of patients with DS with visits to the Massachusetts General Hospital DS Program (MGH DSP) was conducted quarterly. The impact of a newly implemented protocol created and informed by clinical experts in the MGH DSP including laboratory tests, imaging, referrals, and screening tools for dementia and mental health concerns, was analyzed using statistical process control charts. From December 2021 to December 2022, the MGH DSP developed and implemented a new clinical protocol to screen for dementia in 44 adults with DS, ages 40 and above, at a total of 48 visits. We found high rates of completion of two screening surveys (85% and 81%, respectively) and an 84% adherence to our overall protocol elements by clinical staff. Among those with dementia-like symptoms, medical evaluation was collected and summarized. We show that it is possible to successfully implement a new protocol, including the use of a dementia screener, in line with published evidence-based care guidelines for adults with DS. We present our protocol as one successful approach focused on pre-visit screening for symptoms of dementia and mental health concerns and evaluating for co-occurring medical conditions in adults with DS.

1 | Introduction

Children with Down syndrome (DS) in the United States have care guidance outlined in the American Academy of Pediatrics' (AAP) Clinical Report. (AAP Publications Reaffirmed or Retired 2018; American Academy of Pediatrics. Committee on Genetics 2001; Bull and Committee on Genetics. 2011) Studies show wide variation in adherence to the various recommended care elements in the AAP's report. (Jensen et al. 2021; O'Neill et al. 2018; Santoro et al. 2016, 2018; Skotko, Davidson, and Weintraub 2013; Williams et al. 2017) For adults with DS, past studies have assessed aspects of routine, preventative adult healthcare and found gaps in completion of mammography, colonoscopy, and cervical cancer screening. (Jensen, Taylor, and Davis 2013; Jensen et al. 2021) Given an increased risk for Alzheimer-type dementia (AD) in DS due to triplication of the APP gene, (Antonarakis et al. 2020) with a median age of onset of diagnostic clinical symptoms at 55 years, (Startin et al. 2019) a lifetime risk of neurobiological evidence of disease present in excess of 95% of individuals with DS, and significant associated morbidities and mortality, (Hithersay et al. 2018) a statement of good practice was made to screen for AD in all adults with DS. (Tsou et al. 2020) In the evidence-based clinical practice guidelines published in 2020, Tsou et al. made a "strong"

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

recommendation to screen for AD starting at age 40 years (Tsou et al. 2020).

Although the recommendation to screen for dementia was made, the evidence-based clinical practice guidelines for adults with DS did not detail specifics on how this should be accomplished. Further, since the 2020 publication, no studies that we are aware of had assessed adherence to the recommendation for dementia surveillance. We began this quality improvement initiative within our subspecialty clinic for DS, the Massachusetts General Hospital DS Program (MGH DSP), to study the use of a dementia screening protocol that we created for patients with DS, ages 40 years and older, based on the new universal dementia screening recommendations for adults with DS.

2 | Methods

The MGH DSP within the Division of Medical Genetics and Metabolism at MGH in Boston, MA, is a multidisciplinary specialty program for individuals with DS with a history of assessing, enacting, and evaluating quality control initiatives. (Cabrera et al. 2022; Raffaele et al. 2022; Santoro, Brenner-Miller, et al. 2021; Santoro, Campbell et al. 2021; Santoro, Donelan et al. 2021; Santoro et al. 2022; Wood, Gochyyev, and Santoro 2024) Medical visits include a physician, a social worker, a nutritionist, a self-advocate resource specialist with DS, and a program coordinator. The location has phlebotomy available on-site; bloodwork is ordered during a visit and can be completed on the same day. The MGH DSP has collaborations with neuropsychology and psychiatry for follow-up visits as needed. (Raffaele et al. 2022) Prior to a visit, parents, guardians, or other caregivers (hereafter referred to as "caregiver") complete an electronic intake form with caregiver-reported interval medical history and health surveillance.

Beginning in 2021, our team began a Quality Improvement (QI) initiative focused on adherence to the "Adult Evidence-Based Care Guidelines for DS." (Tsou et al. 2020) A quality improvement team-based approach was used to evaluate barriers and drivers, and to study the success of implementing our own "Dementia Protocol." The QI study team consisted of the clinical team caring for adults with DS in the MGH DSP: the Director of Quality Improvement Research for the MGH DSP (geneticist), the MGH DSP Medical Director (geneticist), an internal medicine-pediatrics primary care physician, two social workers, a neuropsychologist, the MGH DSP program coordinator, and two research coordinators. Team interactions included e-mail communication and meetings conducted in-person or through videoconferencing technology.

2.1 | Baseline

Prior to implementing our Dementia Protocol, clinical team members providing care to adults with DS screened for medical symptoms, mental health symptoms, and asked caregivers about concerns (Cabrera et al. 2022) through a pre-visit electronic intake form and during the subspecialty medical visit focused on DS. Prior to the QI initiative, no standard dementia questionnaire or standardized set of questions to screen for dementia was in use in the MGH DSP. Our Specific, Measurable, Achievable, Relevant, and Time-bound (SMART) aim was to obtain 80% adherence to components of our Dementia Protocol for adults with DS, ages 40 and older, by June 2022 and sustain that level of improvement for 6 months. We created a Key Driver Diagram as we planned our initiative (Figure S1), which focused on communication, coordination, guideline knowledge, and triaging symptomatic individuals for improved access and availability.

2.2 | The Intervention

In 2022, our team developed our Dementia Protocol, a multidisciplinary intervention to address the new recommendation in the 2020 Adult Evidence-Based Care Guidelines for DS, and our team met in person, over Zoom, and communicated by e-mail. The goal of the intervention was to establish a consistent practice among all clinicians in the MGH DSP for annual dementia screening for all adults, ages 40 and older, including a work-up to rule out co-occurring medical conditions through lab work, imaging, sleep studies, audiograms, and ophthalmology referral when dementia symptoms were present. Our Dementia Protocol (Table 1) also included the use of existing screening tools for dementia and mental health, neuropsychological assessment, optional neurology referral, patient/family support, education, and patient and caregiver resources.

2.3 | Screening Instruments

One component of the intervention was a screening tool for dementia. In choosing a screening instrument, our team identified the following priorities for a screener: able to be completed by caregiver, able to be completed and scored prior to the visit (ideally electronically to allow support staff to e-mail the screener to caregivers), produce a score that could be used with existing scoring criteria to identify at-risk patients, and be relatively short in number of items and time. From a literature review, search of instruments in use in clinical trials for DS, and discussion with clinical experts, our team identified the following potential dementia screening tools: the National Task Group Early Detection Screen for Dementia (NTG-EDSD), (Silverman et al. 2021) the Adaptive Behavior Dementia Questionnaire (ABDQ), (Prasher, Farooq, and Holder 2004) the Dementia Questionnaire for People with Learning Disabilities (DLD), (Evenhuis 1996) the Dementia Scale for DS (DSDS), (Huxley, Prasher, and Haque 2000) and the Global Deterioration Scale for DS Population (GDS-DS). (Rodríguez-Hidalgo et al. 2023) We selected the ABDQ because it fit best with our priorities outlined above, and we piloted using the ABDQ with caregivers in clinic. During our pilot, we used the paper version of the ABDQ instrument and administered it with caregivers during in-person clinical visits. Caregivers generally reported understanding the instructions, felt able to answer items, and did so rapidly and easily. As a team, we therefore chose to use the ABDQ within our Dementia Protocol intervention.

The ABDQ is a validated questionnaire designed specifically to screen for dementia in adults with DS, consisting of 15 questions, with 4 bipolar Likert response options of "better than normal," "same as normal," "worse than normal," and "much worse than normal." (Prasher, Farooq, and Holder 2004) The ABDQ is derived from the AAMD Adaptive Behavior Scale. (Nihira 1976;

TABLE 1 | Initial Dementia protocol created by the MGH Down Syndrome Program Adult Clinic team and launched in December 2021.

If	Individual with DS age < 40	Individual with DS age ≥ 40 AND asymptomatic	Individual with DS age ≥ 40 AND symptomatic
Then, recommend:			
Neuropsychological evaluation	None related to dementia protocol, but may be needed for other reasons: guardianship, diagnostic clarification, etc.	Conduct baseline neuropsychological evaluation on all patients at age 40, or during first protocol visit if never had a previous neuropsychological evaluation	First, rule out medical and/or mental health causes. Then, refer for a diagnostic neuropsychological assessment if symptoms remain. • If patient is in the late stages of AD, check in with neuropsychologist before referring to determine the necessity of an evaluation at late stage of disease progression. • Repeat neuropsychological assessments, as recommended by neuropsychologists and/or as needed for diagnostic purposes.
Labs	None related to dementia protocol, continue with routine health maintenance		In addition to routine health maintenance, obtain: • Vitamin B12 level • Folate level • Vitamin B1 (Thiamine) level • Complete blood count (CBC) • Thyroid-stimulating hormone (TSH) and Free T4 level • Rapid plasma regain (RPR) test • Human immunodeficiency virus (HIV) test • Celiac Screen (tissue transglutaminase IgA (tTg IgA) and Total IgA) • Consider: Homocysteine—if patient has a history of hypertension or if focal neurological signs are present on exam, raising concerns for cerebrovascular accident etiology. • Consider: Urinalysis and Urine culture if acute on chronic mental status changes are present.
Imaging and procedures	None related to dementia protocol, continue with routine health maintenance		• Imaging: Brain MRI or head CT if neurologic signs • Sleep study: if not previously done, or concern for new OSA symptoms • Hearing and vision screens • Abdominal x-ray if symptoms of constipation
Nutrition	All visits: Standardized measures to assess nutritional status and health habits as well as physical activity level		
Mental wellness screening		Dementia screen: Adaptive Behavior Dementia Questionnaire (ABDQ) annually AND Depression screen: Anxiety, Depression, and Mood Scale (ADAMS), completed by caregivers annually	Dementia screen: ABDQ, completed by caregivers, annually AND Depression screen: ADAMS, completed by caregivers annually

(Continues)

TABLE 1 | (Continued)

If	Individual with DS age < 40	Individual with DS age ≥ 40 AND asymptomatic	Individual with DS age ≥ 40 AND symptomatic
Family support/ resources/education and patient education	All visits: Down syndrome brain train[a], NDSS aging and down syndrome[b], and NDSS Alzheimer's disease in down syndrome[c]		• Alzheimer's association family care guide: A Guide for Families Caring for Someone with Alzheimer's Disease or a Related Dementia[d] • Discuss The Alzheimer's Association Care Consultation Program through local chapter.[e] A social worker can refer or families can self-refer. • National Institute on Aging Home Safety Checklist for Alzheimer's Disease.[f] Also discuss possibility of home safety assessment • For those in group homes/congregate settings, discuss continuing education for staff via Shriver Center (webinars)

[a]"Down syndrome brain train": Offers caregivers evidence-based and expert recommendations on what they can do, right now, to potentially boost cognition and prevent Alzheimer's disease. The topics covered in this series include socialization, exercise, cognitive games, sugar reduction, and the treatment of co-occurring conditions. The series is available at www.downsyndromebraintrain.com.
[b]Aging and down syndrome: A Health & Well-Being Guidebook: This guidebook is a resource for families and caregivers of adults with Down syndrome. It provides accurate information and education about what to anticipate as a part of growing older. It is intended to be used by various learners: families, professionals, direct caregivers, and others. Link: www.ndss.org/wp-content/uploads/2017/11/Aging-and-Down-Syndrome.pdf.
[c]Alzheimer's disease & down syndrome: A Practical Guidebook for Caregivers: This booklet was written to help empower families and caregivers with knowledge about the connection between Down syndrome and Alzheimer's disease, suggestions about how to carefully and thoughtfully evaluate changes that may be observed with aging. Link: www.ndss.org/wp-content/uploads/2017/11/NDSS_Guidebook_FINAL.pdf.
[d]Alzheimer's association family care guide: A Guide for families caring for someone with Alzheimer's disease or a related dementia. This guide shares best practices around communication, daily living, understanding behaviors, safety considerations, planning ahead, and caregiver support. Link: https://www.alz.org/media/manh/documents/alzheimer_s-family-care-guide-(fcg).pdf.
[e]The Alzheimer's association care consultation program is free of charge and available to provide education, support, and care-giving suggestions and guidance to family and care teams. You can self-refer or ask for a referral from the Down Syndrome Program social worker. If you would like to reach out independently, families and caregivers can call 1–800–272-3900. There is Spanish-speaking staff, if needed.
[f]National institute on aging home safety checklist for Alzheimer's disease: Use the following room-by-room checklist to alert you to potential hazards and to record any changes you need to make to help keep a person with dementia safe. Link: https://www.nia.nih.gov/health/home-safety-checklist-alzheimers-disease.

Prasher, Farooq, and Holder 2004) Scores can range from 0 to 111 with higher scores indicating more symptoms of dementia. We screened for co-occurring mental health conditions as the cause or contributor to dementia or mild cognitive impairment (MCI) symptoms. MCI is an early stage of memory loss or other cognitive ability loss that can precede developing dementia. (Petersen et al. 2020) To screen for anxiety, depression, and other mood symptoms, we administered the Anxiety Depression and Mood Scale (ADAMS) to caregivers. (Esbensen et al. 2005) The ADAMS is a validated questionnaire consisting of 28 questions with five subscales: Manic/Hyperactive Behavior, Depressed Mood, Social Avoidance, General Anxiety, and Compulsive Behavior. To match our pre-existing pre-visit workflow (i.e., to enable caregivers time to complete the surveys prior to a clinic visit at the time they were e-mailed pre-visit intake information), we entered the ABDQ and ADAMS items in English into REDCap (Harris et al. 2009) for an electronic mode of administration. Our team piloted these REDCap surveys prior to protocol initiation to ensure working hyperlinks and appropriate formatting.

2.4 | Implementation

The Dementia Protocol implementation began in December 2021. At implementation, administrative staff sent a hyperlink to the items in the ABDQ and ADAMS tools by e-mail to caregivers of all individuals with DS, ages 40 and older, with upcoming scheduled appointments to correspond with the guidance in the 2020 Adult Evidence-Based Care Guidelines for adults with DS. (Tsou et al. 2020) We created calculators in REDCap to tally the ABDQ raw score automatically. The clinic coordinator then reported the raw score to the clinical team at pre-clinic team huddle, which was a multidisciplinary team discussion that took place 30 min prior to the scheduled clinical appointment, as previously described. (Santoro, Brenner-Miller, et al. 2021) During the team huddle, if the ABDQ was not completed electronically before a visit, this was noted, and the clinic coordinator gave the caregiver a tablet computer to complete the survey in-person in the waiting room, if possible. If not, a paper instrument or QR code to the REDCap screener was given for completion by caregiver after the visit.

2.5 | Chart Review

Although the MGH DSP follows patients of all ages, we intermittently reviewed the visit notes for patients, ages 40 and older, in accordance with the 2020 adult DS screening guidelines to follow the impact of our Dementia Protocol. Inclusion criteria were a completed clinic visit to the MGH DSP in

December 2021 or after, regardless of visit format (e.g., telemedicine, phone only, or in-person), and 40 years of age and above. Exclusion criteria were scheduled but not completed visits, encounters outside a clinic visit, and adults with DS with a pre-existing diagnosis of dementia. Individuals whose primary language was not English were not excluded in our chart review; however, the REDCap surveys were available in English only. Data were extracted from finalized visit notes written and signed by the MGH DSP physicians, and included medical record information prior to, but not including, the clinic visit date, along with age, sex, race, and ethnicity. Data were reviewed at least quarterly and presented to the team. The Mass General Brigham Institutional Review Board approved this quality improvement study, and consent was implied by completion of the online survey. Data are available in aggregate, de-identified form at reasonable request.

2.6 | Outcome Measures

Our primary outcome measure was completion of dementia screening, defined as the monthly percentage of patients in MGH DSP ≥ 40 years with a completed ABDQ screen (calculated as the number of patients ≥ 40 years seen for an annual DSP visit with a completed ABDQ/the number of ≥ 40-year patients with documented annual DSP visits). Related to this outcome, to assess our new process, we measured the monthly percentage who had the ABDQ sent to the family by pre-visit e-mail, the monthly percentage who had the ABDQ completed and scored, and the monthly percentage who had the ABDQ score documented in the clinical note. To screen for co-occurring anxiety, depression, and other mood symptoms which could mimic or contribute to dementia or MCI symptoms, we measured the monthly percentage who had the ADAMS sent to family by pre-visit e-mail, the monthly percentage who had the ADAMS completed and scored, and the monthly percentage who had the ADAMS score documented in the clinical note. To track neuropsychological evaluations, we measured the monthly percentage who had ever had a neuropsychological evaluation performed. These three elements were universally recommended in our protocol for all adults ages 40 and older. We also calculated a composite of these three elements.

We calculated overall protocol adherence in reference to the date of clinic visit to the MGH DSP. Each component was scored at each visit as either adherent or not adherent. Adherence was defined as the completion of the component as documented in a MGH DSP physician's visit note or in the electronic health record.

Our protocol also assessed for co-occurring conditions which could mimic or contribute to symptoms of dementia or MCI. We assessed the completion of each individual component of the Dementia Protocol (each individual laboratory test, each individual imaging test, each referral, sleep studies, audiograms, and vision tests). Each component was recorded as ordered, completed, and normal vs. abnormal.

We retrospectively reviewed the medical chart for additional demographic factors, such as age, sex, race, and ethnicity. We searched for assessments of an individual's pre-morbid level of function/baseline IQ or degree of intellectual disability in neuropsychological evaluation reports prior to onset of dementia/MCI symptoms (if any); we documented this if available. The first author (physician) and a clinical research coordinator reviewed visit notes from the visit date to classify adults with DS as symptomatic or asymptomatic. Symptomatic referred to those with a reference in the MGH DSP physician or social work notes of the presence of pre-specified clinical features which could indicate onset of dementia/MCI (e.g., changes in behavior, changes in independence or self-care function, changes in memory, changes in mood or personality). If these were noted, the individual was classified as "symptomatic"; if none were noted, or if positive

TABLE 2 | Demographic information of 44 unique adults with Down syndrome with 48 visits in the first year of implementing a dementia protocol.

Trait	*N* (%)
Sex	
Male	24 (55)
Female	20 (45)
Race	
White	41 (93)
Black or African American	1 (2)
Other	1 (2)
Native Hawaiian or Pacific Islander	1 (2)
Ethnicity	
Not Hispanic	41 (93)
Hispanic	1 (2)
Missing or unavailable	2 (5)
Age (years)	
40–44	8 (18)
45–49	12 (27)
50–54	13 (30)
55–59	5 (11)
60+	6 (14)
Pre-morbid level of function/baseline IQ	
Mild	9 (20)
Mild-moderate	2 (5)
Moderate	20 (45)
Severe	0 (0)
Unspecified or report unavailable	2 (5)
Not completed yet or no referral	11 (25)
Individual with DS is asymptomatic AND age ≥ 40	23 (52)
Individual with DS is symptomatic AND age ≥ 40	21 (48)

notes regarding memory were made (e.g., continues to have good recall for events, faces, dates), the individual was classified as "asymptomatic." Changes which fit with mild cognitive impairment (MCI) were also categorized as "symptomatic" in our project. For any cases with uncertain classification, the visit notes and symptoms were reviewed with the treating DS physician.

2.7 | Analysis

We plotted p-charts using software in Microsoft Excel from a local quality improvement course (Rao et al. 2017) to analyze our newly developed Dementia Protocol through monthly percentages of completion of ABDQ and completion of screens for co-occurring conditions. We tracked the impact of the new protocol for more than 12 months. Centerline shifts were determined using standard statistical process control (SPC) chart rules. (Langley et al. 2009; Provost and Murray 2011) We used the American Society for Quality (ASQ) rules to detect special cause variation on control charts (Tague 2005).

3 | Results

From December 1, 2021 to December 31, 2022 there were 48 eligible visits to the MGH DSP which corresponded to 44 unique adults with DS, all ages 40 and older, with a majority being White and non-Hispanic (Table 2). Mean age was 51.2 years (SD = 6.5 years). Of the 44 adults with DS, 23 were asymptomatic, and 21 had symptoms which the clinical team felt could be related to MCI or dementia.

3.1 | Primary Outcome: Dementia Protocol Implementation

Plotting measures over time, we found our Dementia Protocol to have been effectively implemented: on average, 85% of caregivers completed the ABDQ (Figure S2), 81% of caregivers completed the ADAMS (Figure S3), and 86% of patients had referral for Neuropsychological evaluation (Figure S4). Assessing the sum of these three elements, our total Dementia Protocol composite adherence was 84% (Figure 1). All were stable over time in the first year of implementation without shifts or trends in the data. The month of May 2022 fell outside of control limits but represented a month with few visits. Our related process measures showed that the ABDQ and ADAMS were usually obtained before visits (78% and 79%, respectively) and often documented in the visit notes (78% and 46%, respectively; Table 3).

At these 48 visits, nutrition assessment was conducted at 45 (94%) visits, and family resources in the Dementia Protocol were documented being given in physician or social work notes at 46 (96%) visits.

3.2 | Secondary Outcome: Medical Evaluation for Those With Symptoms of Dementia

Among the 21 adults with DS, ages 40 and older, with symptoms of dementia present, our protocol recommended screening for co-occurring conditions which could mimic or contribute to symptoms of dementia. We found that laboratory evaluations

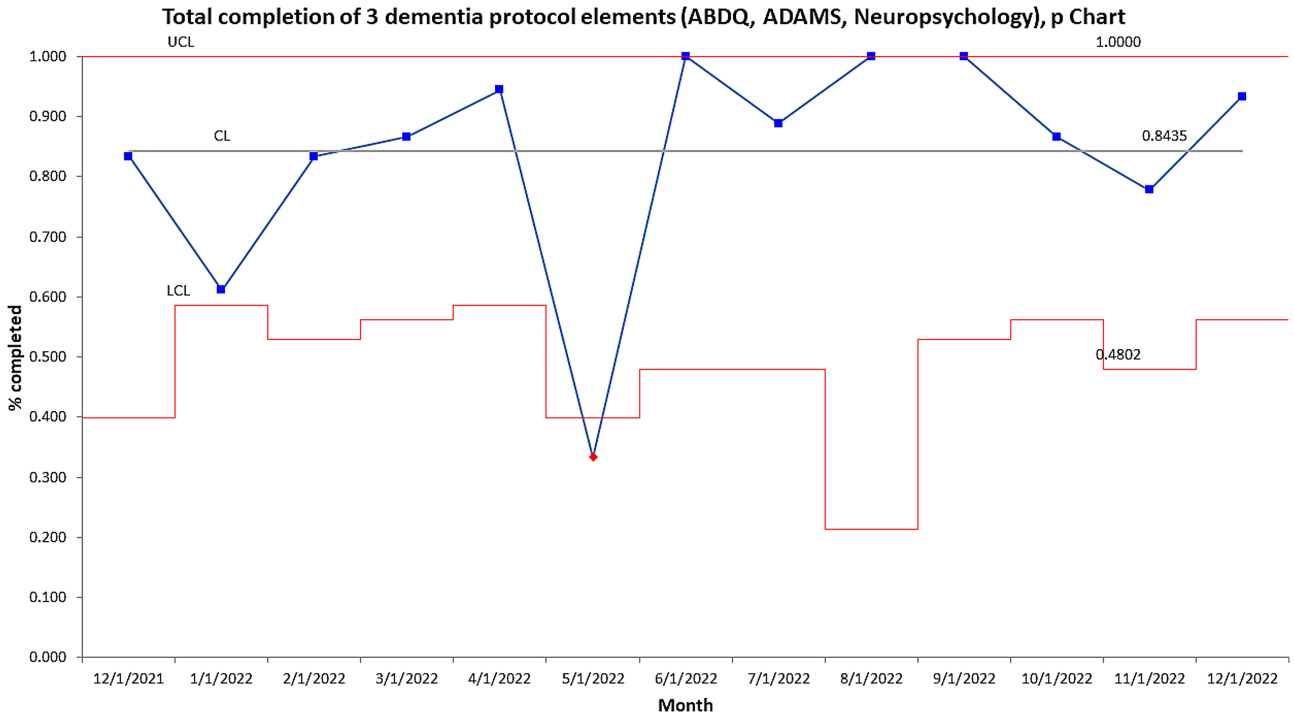

FIGURE 1 | Total adherence rate to 3 guidelines for adults with Down syndrome (Adaptive Behavior Dementia Questionnaire (ABDQ), Anxiety Depression and Mood Scale (ADAMS), and Neuropsychology evaluation) from December 2021 to December 2022. Gray lines indicate the process stage mean, which refers to the arithmetic mean for all points within that process stage; statistical rules indicate that there is 1 stable process stage. Red lines indicate the control limits (±3 SDs based on the process mean and number for that month).

TABLE 3 | Tracking Universal protocol elements that apply to all adults with DS ≥ 40 years in a Quality Improvement Project in the MGH Down Syndrome Program—full first year of data from 48 visits.

Outcome measures	Among patients age ≥ 40 years with a completed visit to MGH DSP, calculated as	Rate
ABDQ screen rate	The number of visits with a completed ABDQ/ the number eligible to complete ABDQ	41/48 = 85%
ADAMS screen rate	The number of visits with a completed ADAMS/ the number eligible to complete ADAMS	39/48 = 81%
Neuropsychology referral rate	The number of visits with a completed Neuropsychology referral/the number age ≥ 40 years	41/48 = 85%
Process measures:		
ABDQ pre-visit rate	Of those with a completed ABDQ, the number of ABDQ completed pre-visit/the number of visits with a completed ABDQ	32/41 = 78%
ADAMS pre-visit rate	Of those with a completed ADAMS, the number of ADAMS completed pre-visit/the number of visits with a completed ADAMS	31/39 = 79%
ABDQ visit rate	Of those with a completed ABDQ, the number of ABDQ completed on visit day/the number of visits with a completed ABDQ	4/41 = 10%
ADAMS visit rate	Of those with a completed ADAMS, the number of ADAMS completed on visit day/the number of visits with a completed ADAMS	4/39 = 10%
ABDQ other time rate	Of those with a completed ABDQ, the number of ABDQ completed at another time/the number of visits with a completed ABDQ	5/41 = 12%
ADAMS other time rate	Of those with a completed ADAMS, the number of ADAMS completed at another time/the number of visits with a completed ADAMS	4/39 = 10%
ABDQ score rate	Of those with a completed ABDQ, the number of ABDQ documented in visit note/the number of visits with a completed ABDQ	32/41 = 78%
ADAMS score rate	Of those with a completed ADAMS, the number of ADAMS documented in visit note/the number of visits with a completed ADAMS	18/39 = 46%

were frequently completed, procedures were often performed, and imaging was infrequent (Table 4). Abnormal results were seen on sleep studies and hearing tests but were often already being treated and well-controlled medically. Overall, this, medical evaluation often did not provide a clear medical explanation to fully account for dementia or MCI symptoms, but a few abnormal results could not be excluded as a contributor to dementia symptoms (Table 4). For example, one person with DS had an abnormal non-contrast head CT scan which showed chronic findings most likely due to chronic microvascular ischemia, but this person had a subsequent CT scan 3 years later which was unchanged and continued to show chronic small vessel ischemic disease (Table S1). Although chronic strokes are a known cause of dementia (e.g., vascular dementia), that person did not carry a diagnosis of nor had been treated for chronic strokes. Of the individuals with abnormal sleep studies and obstructive sleep apnea, at many of the visits ($N = 10$), they were already receiving treatment (e.g., consistent use of continuous positive airway pressure (CPAP) mask), but for some individuals, wearing a CPAP mask could not be tolerated, use of CPAP was declined, or CPAP was not yet prescribed (Table 4) leading to some ambiguity (i.e., "cannot exclude") about the extent that chronic, untreated OSA could be contributing to some of the AD symptoms.

4 | Discussion

The U.S. Preventive Services Task Force and the American Academy of Family Physicians have concluded that current evidence is insufficient to assess the benefits versus. harms of screening for cognitive impairment in older adults. (Falk, Cole, and Meredith 2018) If dementia is suspected, brief clinical screening tests such as Mini-Cog or General Practitioner Assessment of Cognition are available for physicians; however, given the absence of universal dementia screening guidelines for adults, data on the uptake of dementia surveillance in the general population is lacking. Based on the association between AD and DS, (Antonarakis et al. 2020; Hithersay et al. 2017, 2018; Startin et al. 2019) a "strong recommendation" was made in the evidence-based clinical practice guidelines to screen all adults with DS for AD annually beginning at age 40 years (Tsou et al. 2020). Our paper describes a protocol to implement dementia screening in DS and evaluates adherence to the statements of good practice made by (Tsou et al. 2020).

In this quality initiative, we began a project to implement a dementia screening protocol for adults with DS in a specialty DS clinic. We developed a novel Dementia Protocol which we share with other physicians who care for adults with DS. Tracking

TABLE 4 | Completion of symptom-based dementia protocol components at 25 visits for 21 unique symptomatic adults with Down syndrome, ages 40 and older.

Dementia Protocol component. For adults with DS ≥40 years AND symptoms of dementia	Not ordered or done ever, *N*	Ordered after MGH DSP visit, *N*	Ordered on MGH DSP visit date, *N*	Ordered, but not completed, *N*	Completed, more than 1 year ago, *N*	Completed, within the last year, *N*	Total Completed ever during 25 visits, *N* (%)	Completed and Abnormal, *N*	Completed and Normal, *N*	Explains dementia symptoms?, Y/N/Can not exclude, *N*
Laboratory tests										
TSH +/− Free T4	2	2	10	0	2	9	23 (92)	3	20	0/3/0
CBC	0	2	12	1	2	9	24 (96)	18	6	0/18/0
Celiac Screen (tTg IgA)	6	1	7	0	5	6	19 (76)	2	17	0/2/0
Vitamin B12	5	2	9	2	0	9	18 (72)	1	17	0/1/0
Folate	10	0	5	1	6	4	14 (56)	2[a]	12	0/2/0
Vitamin B1 (thiamine)	15	1	6	3	0	3	7 (28)	2[a]	5	0/2/0
Homocysteine	17	0	2	1	5	1	7 (28)	1[a]	6	0/1/0
HIV	20	0	0	0	4	1	5 (20)	0	5	0/0/0
RPR	19	0	5	2	1	0	4 (16)	1[a]	3	0/1/0
Urinalysis +/− Urine culture	12	0	0	0	7	6	13 (52)	5[c]	8	0/5/0
Imaging										
Brain MRI	22	0	0	0	2	1	3 (12)[d]	1	1	0/1/0[e]
Head CT	19	0	0	0	3	3	6 (24)	5	1	0/3/2[e]
Abdominal x-ray	20	0	0	0	4	1	5 (20)	4	1	0/4/0[e]
Procedures										
Sleep study	6	0	3	6	15	1	16 (64)	15[b]	1	0/10/5[f]
Hearing test	2	2	4	2	10	7	16 (64)	13[b]	3	0/13/0
Vision test	10	0	1	0	5	9	18 (72)	16[b]	2	0/16/0

[a]These abnormal values were nondiagnostic including high folate and high B1 (thiamine), RPR was false positive on subsequent testing, and homocysteine level of 14 (lab reference range < 13 = normal) asymptomatic/no clotting.
[b]Of these with abnormal tests, some were treated subsequently through the use of surgery, CPAP, or use of hearing aids or glasses.
[c]One patient had recurrent UTIs that were treated; ultrasound, cystoscopy and was started on prophylactic antibiotics. Last UTI was in 2017—i.e., urine symptoms were treated/stopped, but AD symptoms continued.
[d]One patient had brain MRI completed but report/result was not available for review.
[e]Please see Table S1 for details on Imaging results.
[f]Of the 15 visits with abnormal sleep studies, most (10) were wearing CPAP consistently and OSA was treated. At four visits, the patient could not tolerate CPAP, CPAP declined, or they were awaiting a CPAP initiation visit.

outcome measures, we found that completion of our three universal measures for all adults with DS aged 40 and older (screen with ABDQ, screen with ADAMS, and referral for baseline neuropsychological evaluation or past neuropsychological evaluation) were high. This aligns with our clinic's past QI work and continued practice improvement model. (Cabrera et al. 2022; Santoro, Brenner-Miller, et al. 2021; Santoro, Donelan et al. 2021; Santoro et al. 2022).

Screening to identify dementia or MCI in adults with DS has implications on medical care, and we are hopeful that our experience and Dementia Protocol will be useful to others and lead greater awareness and standardized dementia screening in this high-risk population. Screening is a necessary first step before diagnosis and treatment. Though there have been large randomized, placebo-controlled trials for patients with early-stage AD, adults with DS, who experience high rates of AD, have not been included in any of these trials. (Rafii and Fortea 2023) Only a small number of clinical trials for AD have included participants with DS. (Rafii and Fortea 2023).

Our data describe a single institution DS specialty clinic quality improvement initiative and may not generalize to other DS clinics, other specialty clinics, or primary care practices. This study was limited by the small sample size and the lack of baseline measures as this was a novel protocol, we did not have baseline data to demonstrate improvement. Although having baseline data would be interesting to help describe the pre-guidelines landscape, our goal was to describe the QI implantation process we underwent at our DS clinic implementing the dementia screening guidelines after the guidelines were released in 2021 and not to test the pre-post difference in screening rates.

It is nevertheless important to describe our experience with successfully creating, implementing, and following a screening protocol for dementia in adults with DS to demonstrate the feasibility of implementation. We used a validated instrument, the ABDQ, but a similar dementia screening protocol utilizing electronic pre-visit, caregiver-reported information could likewise be used with other instruments or measures, such as the NTG-EDSD, among others (Silverman et al. 2021). Although overall rates of completing ADAMS and ABDQ were high (81% and 85%, respectively), we saw that clinician documentation of the completed ADAMS was relatively low (46%) compared to the documentation of ABDQ (78%). This is likely because our primary focus was on dementia screening, and the ADAMS is a screener for other mental health conditions. In our protocol, we had created an electronic health record note phrase (called a "dotphrase" in the Epic electronic health record system), which prompted the physician to document the ABDQ results and interpretation. The dotphrase did not similarly prompt the physician to document the ADAMS results. Going forward, we plan to update this to also include the ADAMS results to more consistently document and track to see this intervention. As we continue to modify our current protocol, we will continue to monitor and follow protocol adherence.

An established screening protocol enables future studies to determine if earlier screening through an established protocol leads to earlier diagnosis or available supports. In the future, it would also be helpful to investigate the impact of interventions to prevent and treat MCI or dementia for people with DS, as they become available. Future study could evaluate the impact of treating medical conditions (e.g., co-occurring sleep apnea) and symptoms of AD to tease apart the interplay of AD and other co-occurring medical conditions in DS. We are hopeful that this work can serve as a framework for other clinicians planning to implement a dementia screening protocol for adults with DS based on the latest evidence-based care guidance (Tsou et al. 2020).

5 | Conclusion

We describe the successful development and implementation of a quality improvement initiative to screen for AD in adults with DS ages 40 and older without pre-established diagnosis of dementia.

Author Contributions

Stephanie L. Santoro: conceptualization, methodology, formal analysis, and writing – original draft, review, and editing. Ayesha Harisinghani: data acquisition and curation, project organization and administration, writing – review and editing. Caroline Bregman: conceptualization, review of data curation, writing – review and editing. Clorinda Cottrell: conceptualization, review of data curation, writing – review and editing. Margaret B. Pulsifer: conceptualization, methodology, review of data curation, writing – review and editing. Mikayla Shaffer: data acquisition and curation, project organization and administration, writing – review and editing. Amy Torres: Data acquisition and curation, project organization and administration, writing – review and editing. Brian G. Skotko: methodology, writing – review and editing. Nicolas M. Oreskovic: conceptualization, methodology, review of data curation, and writing – review and editing.

Conflicts of Interest

S.L.S. has received research funding from LuMind Research Down Syndrome Foundation to conduct clinical trials for people with Down syndrome within the past 2 years. She serves in a non-paid capacity on the Medical and Scientific Advisory Council and the Board of Directors 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. M.B.P. received funding from the National Institutes of Health to conduct research with people with Down syndrome 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. B.G.S. occasionally consults on the topic of Down syndrome through Gerson Lehrman Group. He receives remuneration from Down syndrome non-profit organizations for speaking engagements and associated travel expenses. Within the past 2 years, B.G.S. received annual royalties from Woodbine House Inc., for the publication of his book, *Fasten Your Seatbelt: A Crash Course on Down Syndrome for Brothers and Sisters*. Within the past 2 years, he has also received research funding from AC Immune and LuMind IDSC Down Syndrome Foundation to conduct clinical trials for people with Down syndrome. B.G.S. is occasionally asked to serve as an expert witness for legal cases where Down syndrome is discussed. B.G.S. serves in a non-paid capacity on the Honorary Board of Directors and the Medical Scientific Advisory Board for the Massachusetts Down Syndrome Congress and the Board of Directors for the T21 Research Society. B.G.S. has a sister with Down syndrome. N.M.O. serves in a non-paid capacity on the Medical Scientific Advisory Board for the Massachusetts Down Syndrome Congress. The other authors declare no conflicts of interest.

Data Availability Statement

Data are available in aggregate, de-identified form at reasonable request.

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Supporting Information

Additional supporting information can be found online in the Supporting Information section.