

**RESEARCH ARTICLE**

Transition to virtual clinic: Experience in a multidisciplinary clinic for Down syndrome

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Abstract

The COVID-19 pandemic necessitated a rapid transition from in-person office visits to virtual visits in the Down syndrome specialty program at Massachusetts General Hospital (MGH DSP). We describe the clinic transition to virtual visits in April 2020 and reflect on our six-month experience in virtual visits. Clinic metrics were tracked. Electronic survey responses were collected from caregivers attending virtual visits. Input from the MGH DSP team was collected. From April to September 2020, we maintained patient volume (45 visits per month) and overall satisfaction score (6.7 out of 7) following a sudden, unanticipated transition to virtual visits. Survey of 17 caregivers attending virtual visits found that most were equipped with technology, had access to a private location, and most were able to access visit without any limitations. Caregivers appreciated the convenience of virtual visits but sometimes missed the personal connection of an in-person visit. Overall, though, virtual visits were frequently viewed as no different than office visits. Team members identified benefits and challenges of virtual visits, as well as lessons learned from this transition. We were able to maintain multidisciplinary, specialty care with optimal caregiver feedback and sustained number of patient visits.

1 | INTRODUCTION

With the onset of the COVID-19 pandemic in the United States, there have been significant impacts on the way that medical care is provided (McMichael et al., 2020). In some instances, this may result in the use of telemedicine. Although this has likely been wide-spread across many hospitals, settings, and clinics, published examples show that COVID has led to reinvention of how palliative care is delivered (Ritchey, Foy, McArdel, & Gruenewald, 2020), how patients with chronic kidney disease are cared for (Chen et al., 2020), and even how obstetric care can be delivered virtually to reduce in-person visits (Fryer, Delgado, Foti, Reid, & Marshall, 2020).

Prior to the COVID-19 pandemic, we knew that patients with Down syndrome (DS) have differences in respiratory infections compared to the general population (Santoro et al., 2020). In childhood, pneumonia is the primary cause of hospital admissions for patients with DS, and lower respiratory tract infections accounted for 40% of

admissions (Hilton, Fitzgerald, & Cooper, 1999). Children with DS and concurrent RSV infection are at increased risk for hospitalization, mortality, and need for mechanical ventilator support compared to controls (Beckhaus & Castro-Rodriguez, 2018). In adults with DS, there was an increased incidence of pneumonia and respiratory failure in comparison to controls (Uppal, Chandran, & Potluri, 2015), and pneumonia has been known to be a leading cause of death in DS for decades (Weiner & Stimson, 1948).

During the COVID-19 pandemic, one study found that people with intellectual and developmental disabilities (IDD) had higher prevalence of specific comorbidities associated with poorer COVID-19 outcomes, and age-related differences in COVID-19 trends were present with a higher concentration of COVID-19 cases at younger ages (Turk, Landes, Formica, & Goss, 2020). As adults with IDD may live in congregate care settings, one study of the first 100 days of the COVID-19 pandemic found that adults with IDD can benefit from a coordinated approach to infection control, case identification, and

cohorting (Mills et al., 2020) Specifically for those with DS, survey has shown that the signs and symptoms of COVID-19 infection in DS are similar to the general population; in people with DS, the risk for fatal outcomes begins in the 40s, at an earlier age than the general population (COVID-19 and Down Syndrome T21RS Survey, Report May 27, 2020, 2020; Hüls et al., 2020).

Telemedicine is one approach during the COVID-19 pandemic to provide safe access to care and has long been considered an option to expand care, especially in rural areas (Güler & Ubeyli, 2002). Previously, implementation of virtual video visits in five specialties at Massachusetts General Hospital found that initial experiences were positive for both patients and clinicians; for most encounters, these video visits were just as clinically effective and less expensive for both patient and provider compared with in-person visits (Donelan et al., 2019). Within the population of children with special health needs, telemedicine may minimize barriers such as the need for special transportation such as a vehicle with wheelchair capacity, special equipment, or attendants, including multiple adult caretakers or a professional nurse (Langkamp, McManus, & Blakemore, 2015). Challenges of telemedicine can include equipment limitations, documenting in multiple platforms, and tech literacy (Langkamp et al., 2015; Trubitt et al., 2018). One school-based program using asynchronous telemedicine to connect children with IDD with their primary care physician found a high level of satisfaction, decreased stress to the child, and concluded that telemedicine may actually be superior to traditional in-office visits in some circumstances (Langkamp et al., 2015).

In March 2020, as cases increased in Massachusetts and our hospital system responded to the COVID-19 pandemic, the Mass General Hospital Down Syndrome Program (MGH DSP) transitioned quickly to a fully virtual clinic. The goal of this project is to describe our experience in telemedicine in a DS specialty clinic, and our experience in transitioning our multidisciplinary, subspecialty clinic from an in-person clinic to a virtual clinic. The aims of this study were to (a) determine if the clinical capacity could be maintained (i.e., are we able to continue to meet the needs of our patients?), (b) evaluate caregiver feedback on the quality of our virtual clinic, comparing to previous in-person visits when able, and (c) share input from team members to identify challenges in this transition and lessons learned. This information may prove of useful to geneticists who lead similar multidisciplinary clinics and are identifying ways that they can integrate telemedicine. As clinics weigh the decision to return to in-person clinic, and seek to provide the best care possible in virtual settings, this summary of our virtual experience may be of interest. The “new normal” for genetics clinics might certainly include elements of virtual experiences such as ours.

2 | METHODS

2.1 | The setting

The MGH DSP provides comprehensive care to a large volume of patients with DS. In total, we follow 550 unique patients annually, of

whom 265 are age 0–21. The MGH DSP provides care for infants, children, adolescents, and adults with DS as well as prenatal consultation for expectant parents. The MGH DSP has distinct clinics by age group: Infant and Toddler Clinic (ages birth–5 years), Child Clinic (ages 5–13 years), Adolescent and Young Adult Clinic (ages 13–21 years), and Adult Clinic (ages 21 years and older).

Prior to the COVID-19 pandemic, the MGH DSP provided in-person specialty care. Clinic occurred in a dedicated space with specific clinic days allocated to a given age range. On average, at least 10 clinic visits occurred each week. The multidisciplinary clinic included the following team members: physician, social worker, nutritionist, speech therapist, occupational therapist, physical therapist, psychiatrist, psychologist, neuropsychologist, an educational advocate, a resource specialist, program manager and others. National experts from Massachusetts General Hospital, Mass General Hospital for Children, and Massachusetts Eye and Ear Infirmary work together to provide care for people with DS. Our team previously communicated with families electronically through e-mail, the electronic health record, and electronically obtained caregiver feedback.

2.2 | Clinic transition to virtual

The MGH DSP transitioned quickly to a fully virtual clinic in March 2020. In our Results section, we outline our process in transition from in-person clinic to virtual clinic. Through retrospective reflection in August 2020, our team highlights on phases of planning, launching, making adjustments, lessons learned, and establishing a “new normal” for our clinic procedures.

2.3 | Clinic metrics

To determine if the clinical capacity has been maintained (i.e., if we are able to continue to meet the needs of our patients) with transition to virtual video visits, we tracked clinic outcomes such as our clinic volume and number of no-shows to a virtual video visit. Clinic volume was calculated by counting the number of kept visits per month; this included any scheduled visit for which the caregiver and patient arrived to the virtual video visit and the visit was completed successfully. No-show visit number was calculated by counting the number of visits which were scheduled, but which the caregiver or patient did not arrive to the virtual video visit. Other visits were noted, such as visits in which the caregiver or patient arrived, but the visit could be not completed, if a visit had to be completed by phone rather than video, or if a patient/caregiver canceled their visit within 1–2 days of their scheduled visit.

2.4 | Caregiver telemedicine survey

Prior to the COVID-19 pandemic, the MGH DSP routinely requested caregiver feedback through an electronic survey, which is sent by e-

mail approximately 2 weeks after a visit. This survey was sent to all English-speaking caregivers with an e-mail on file. The survey consists of a general question: "Overall, how would you rate your experience?" with responses from 1–7 with 1 being "terrible," 4 being "neutral," and 7 being "wonderful." There are open response questions to ask about what worked well and what the caregiver would like to see improved.

In March 2020, we created an additional section in this electronic survey, which focused on the experience with telemedicine. This telemedicine survey was created from an adaptation of a survey previously validated in the general population (Donelan et al., 2019). Team members reviewed the survey for applicability to our clinic model, virtual visits, and our patients with DS. A caregiver of a child with DS reviewed the survey for face validity and readability. This electronic survey was sent to all patients who had a virtual visit after onset of COVID-19 pandemic.

2.5 | Team input

During a scheduled meeting for the MGH DSP team, we asked team members to reflect on the transition to virtual clinic.

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 restrictions, as sharing of responses was not disclosed prior to survey completion. The Partners Institutional Review Board approved this study.

3 | RESULTS

3.1 | Clinic transition to virtual

As the MGH DSP transitioned to a fully virtual system, the first phase focused on planning. Weighing many factors, including unknown variables, our clinic director made the decision to move our clinic to full-virtual operations. Some of the factors that were weighed were the safety of our patients, families, and the clinical team, the distance that some families need to travel and the risks of travel given COVID-19 travel bans and regional differences in infection prevalence or test availability, and the need for team members to balance work-life demands and childcare. For 2 weeks in March, our team prepared for the transition to virtual clinic, which consisted of twice weekly virtual team meetings to address technology concerns, illness/health concerns, and other agenda items. The MGH DSP also continued weekly team lunches virtually. Our operations were all conducted through Zoom, and time was spent on training in Zoom and practicing using the functions of the platform such as breakout rooms and waiting room function. Zoom enables HIPAA compliance and we did not experience any HIPAA issues (*HIPAA Compliance Datasheet*, 2020). Scheduling occurred in Outlook using the Zoom plug-in, and time was also spent practicing this process to ensure that all physicians and nutritionists were creating a visit in the same manner for consistency.

The scheduling templates remained the same from before the COVID-19 pandemic to the virtual model; clinic appointment slots remained at either 30- or 45-minutes in length based on the scheduling template. The MGH DSP resource specialist converted some of his handouts to recorded Zoom videos and developed a new process to send personalized e-mails to each patient. The MGH DSP includes four physicians, and one was pulled from outpatient clinic to inpatient care of COVID-19 patients.

When launching the new virtual clinic workflow, schedulers would call to let families know we were converting to virtual video visits, to ask if the family had access to a device (i.e., smartphone, tablet, laptop, or computer), and to obtain their e-mail. The physician or nutritionist would create a calendar invite for each appointment that included the Zoom logistics; this was then sent to MGH DSP scheduler and other multidisciplinary team members. The MGH DSP scheduler then e-mailed the appointment time, Zoom links with back-up phone information, and a tip sheet to the family. If an interpreter was needed, our scheduler pre-scheduled with MGH Interpreter Services, and shared this information with team.

On March 31, 2020, the MGH DSP held its first virtual visit. For 30 min prior to the first patient, the team held its typical team huddle on Zoom prior to start of clinic. All multidisciplinary team members then logged in to see their first patient. The leader (either a physician or nutritionist) then admitted all multidisciplinary team members first from the waiting room, including interpreters if applicable. When ready, the family and patient was then admitted from the virtual waiting room. In addition to typical clinic follow-up e-mails and electronic orders, the administrative team assisted with coordinating outpatient lab work and referrals.

The MGH DSP created electronic newsletters that were posted 3–4 times per week. The newsletters incorporated themes related to the COVID-19 pandemic and health content aimed at Wellness, Movement, Fun, and Self-Care. These virtual newsletters were distributed through the MGH DSP e-mail list and posted on social media.

As the virtual clinic continued in practice, and the team gained experience in this new workflow, adjustments occurred. One addition was to re-incorporate our pediatric therapy team (PTT), consisting of our team's physical therapist, occupational therapist, and speech therapist, to assess patients under age 5 years. In these virtual PTT evaluations, therapists were able to continue to provide expert recommendations on services needed and to assess developmental progress. Through the COVID-19 pandemic, out-of-state regulations changed regarding licensing, insurance reimbursement, and policies about care through specialty clinics which were not available in other states; we remained agile to follow these regulations with rescheduling and offering alternatives to virtual visits. The MGH DSP continued to incorporate residents and observers in the virtual visits, using functions to allow genetic residents to have independent time with patients and present to the attending physician. Beginning in April 2020, a previously planned clinic expansion consisted of additional clinic times and incorporated new team members.

Throughout the transition, we have found consistency and routine in the new virtual clinic model and a feeling of attaining a "new

normal.” As of November 2020, we continue to plan for virtual visits for the next months and beyond. We have identified some situations which may benefit from an in-person visit rather than a virtual visit, including: patients who have scheduled visits for in-person services such as audiology or ophthalmology, patients who do not have a video-interpreter available, or patients who have complex needs.

3.2 | Clinic metrics

To determine if the clinical capacity has been maintained, that is, if we are able to continue to meet the needs of our patients, we calculated clinic volume by counting the number of kept visits per month. On average, 50 visits per month (range 38–57) were scheduled during the first 6 months of our virtual transition from April to September 2020 (Figure 1). The average wait time to first appointment was 237 days and did not significantly change in our six-month virtual transition (Figure 2). We had an average of 5.5 no-show visits per month from 2018 to 2020, which did not significantly change in our 6 months of virtual transition (Figure 3).

3.3 | Caregiver Telemedicine survey

The MGH DSP has consistently requested caregiver feedback since 2013; our baseline scores on overall experience as rated by caregivers, with “1” being “terrible,” “4” being “neutral,” and “7” being “wonderful”, is positive with an average score of 6.5 out of 7 (92%) in 2017-2020 prior to virtual clinic (Figure 4).

To evaluate caregiver feedback on the quality of the virtual clinic experience, we e-mailed the survey hyperlink to all who had a virtual visit. We received 17 responses. When asked how caregivers would

rate their experience overall during the first 6 months of virtual transition, with “1” being “terrible,” “4” being “neutral,” and “7” being “wonderful”, caregivers rated an average score of 6.67 out of 7 (95%) which did not vary from our baseline using Statistical Process Control (SPC) rules (Langley et al., 2009).

Most respondents were mothers of individuals with DS. Many of our caregivers were familiar with virtual visits prior to the visit with MGH DSP; all were either very or somewhat comfortable with technology. All had the technology they needed and a private location for the virtual visit (Table 1).

In general, the virtual visit was completed with success (Table 2). One respondent felt it was somewhat difficult to access Zoom. Few problems were identified, including one respondent had trouble joining the Zoom visit initially, one respondent had trouble remaining connected during the visit, and one respondent had trouble with video. Sixteen of 17 would recommend a virtual visit to family and friends.

In comparing a virtual video visit to an in-person visit, some caregivers found that some features of a visit were better in virtual visits, but responses regarding overall quality of the visit were most often no difference or better in an office visit (Table 3). Some features which were better in a virtual visits included a convenient time, childcare or elder care arrangements, travel, coordination, and wait time. Some features which were better in an office visit were personal connection with a clinician and the ability to show a clinician a physical problem.

In an open-ended question asking what went well, caregivers highlighted communication, the quality of medical care and insight of multidisciplinary team, the ease and the decreased stress of not driving and parking, as well as being able to access an appointment from work and home.

In an open-ended question about what could be improved, one caregiver identified consistency in log-in directions, one caregiver

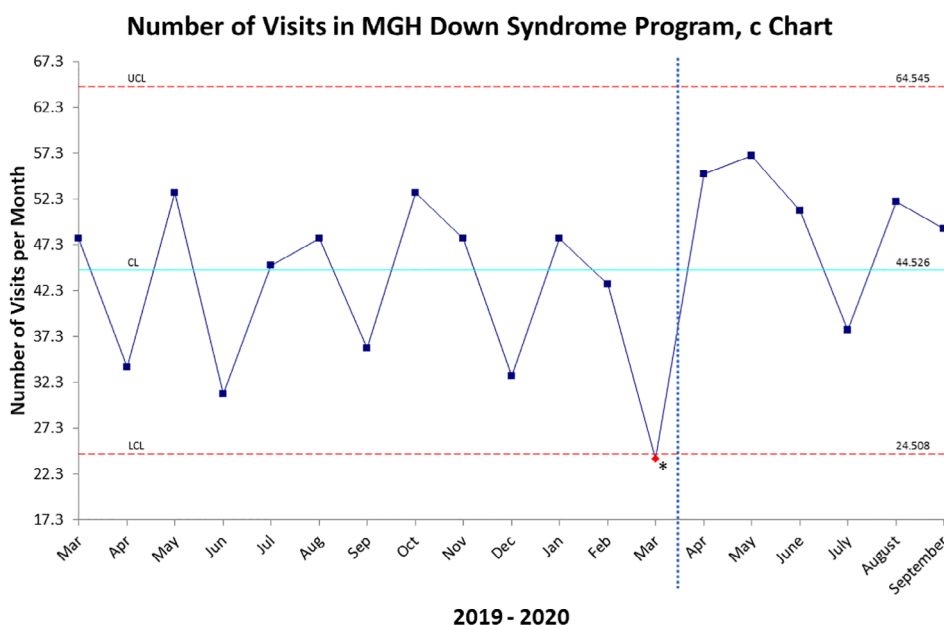


FIGURE 1 Monthly number of clinic visits in the Mass General Hospital Down Syndrome Program, c Chart, from 2019 to 2020. Solid lines indicate the process stage mean, which refers to the arithmetic mean for all points within that process stage; statistical rules indicate that there is 1 stable process stage. Red lines indicate the control limits (± 3 SDs based on the process mean and number for that month). Dotted blue lines indicate the transition to virtual visits

Wait for first appt (days) in the MGH Down Syndrome Program from 2014 to 2020, c Chart

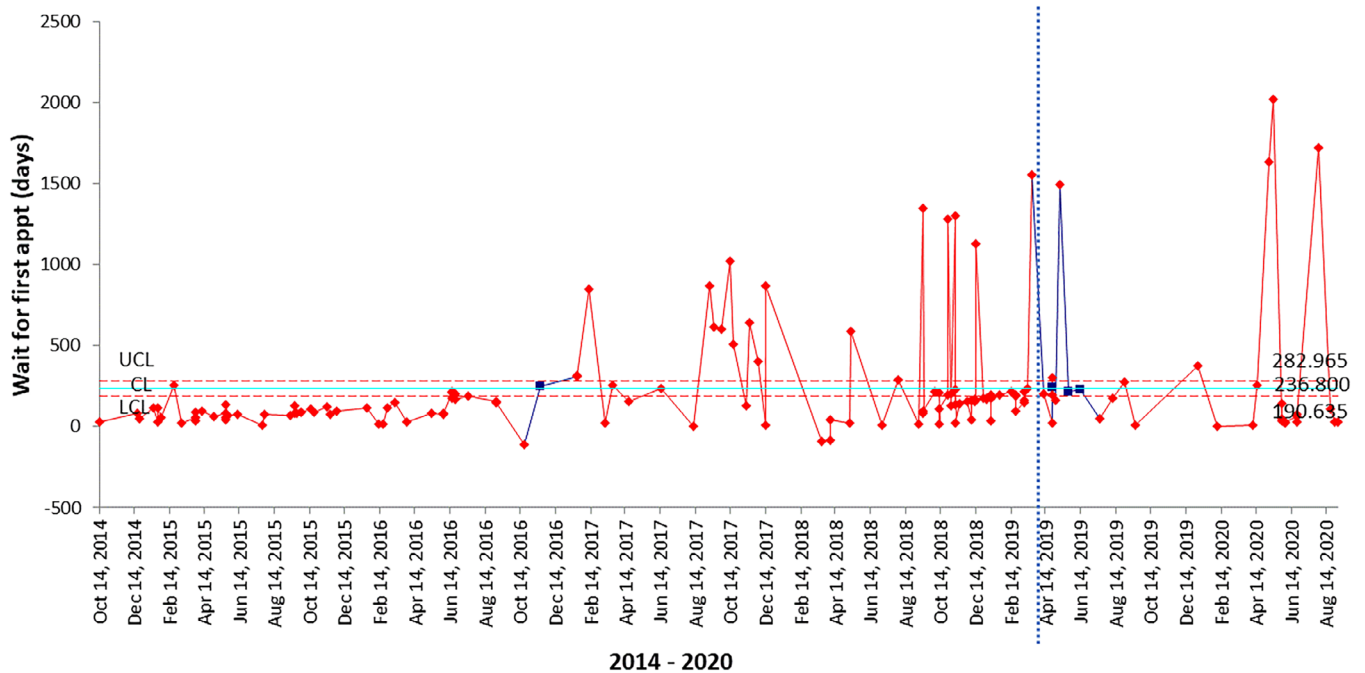


FIGURE 2 Wait time for first appointment (days) in the Mass General Hospital Down Syndrome Program, c Chart, from 2014 to 2020. Solid lines indicate the process stage mean, which refers to the arithmetic mean for all points within that process stage; statistical rules indicate that there is 1 stable process stage. Red lines indicate the control limits (± 3 SDs based on the process mean and number for that month). Dotted blue lines indicate the transition to virtual visits

of No Show Visits per Month in the MGH Down Syndrome Program, c Chart

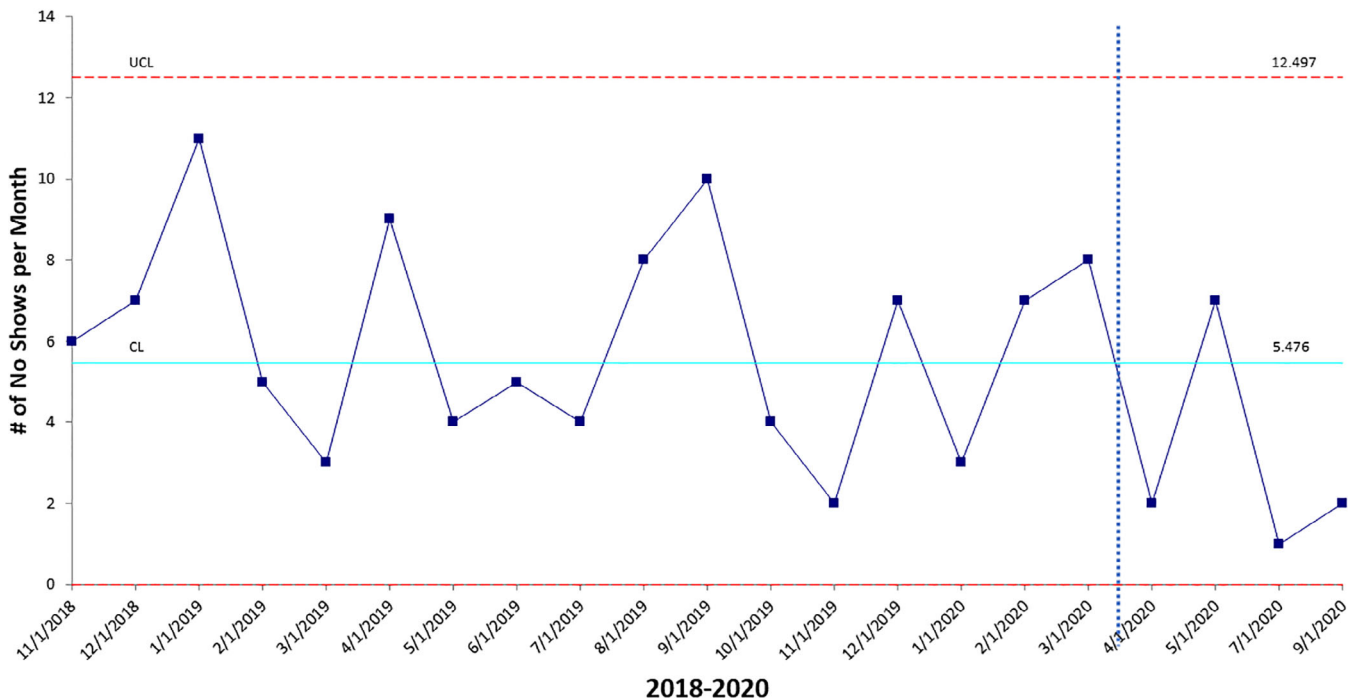


FIGURE 3 Number of No Show visits per month in the Mass General Hospital Down Syndrome Program, c Chart, from 2018 to 2020. Solid lines indicate the process stage mean, which refers to the arithmetic mean for all points within that process stage; statistical rules indicate that there is 1 stable process stage. Red lines indicate the control limits (± 3 SDs based on the process mean and number for that month). Dotted blue lines indicate the transition to virtual visits

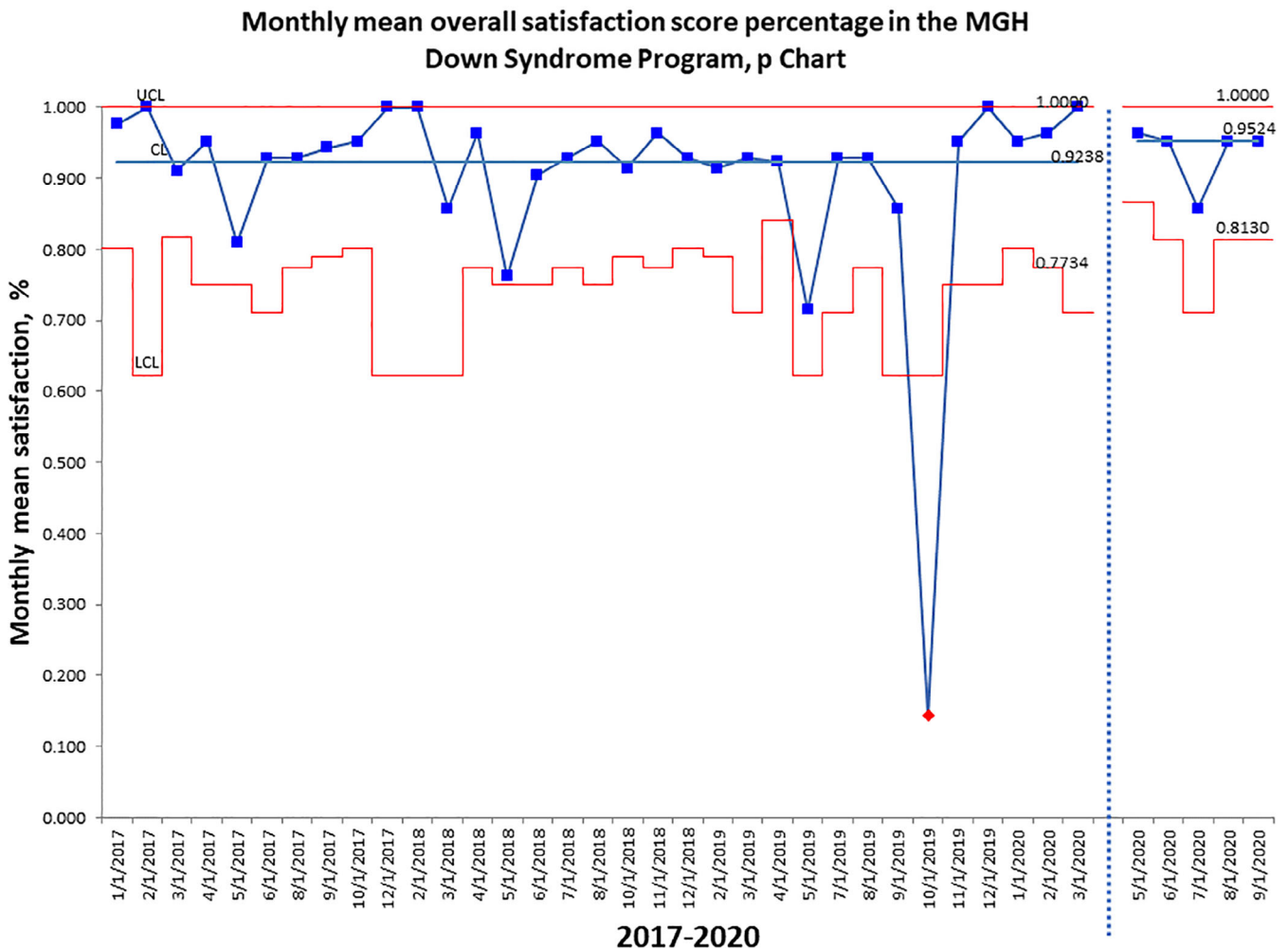


FIGURE 4 Monthly mean overall satisfaction score percentage in the Mass General Hospital Down Syndrome Program, p Chart, from 2017 to 2020. Break in April 2020 shows transition to virtual clinic, with no shift or special cause variation. Solid lines indicate the process stage mean, which refers to the 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). Dotted blue lines indicate the transition to virtual visits. *the positive comments did not seem to match the rating of “1” given

identified more time needed, two caregivers commented on difficulty with blood draws and others were blank or gave positive comments that nothing needed to be improved.

3.4 | Team input

Team members identified challenges in this transition and lessons learned highlighting themes of telemedicine strengths and limitations (Table 4).

4 | DISCUSSION

Although telemedicine has been gaining traction for some years, the COVID-19 pandemic accelerated its uptake due to its public health

implications, local legislations, and hospital policy. Our multidisciplinary clinic specializing in care of patients with DS across the lifespan made the decision to transition our model from fully in-person to fully virtual in a matter of weeks, and have sustained this change for months. In this transition, we followed our clinic metrics, surveyed caregivers, and sought team input to capture the lessons we have learned along the way which may be useful for others who may be transitioning multidisciplinary clinics to virtual workflows, or are looking to improve current virtual models. The MGH DSP was able to

- Transition to full virtual workflows, maintaining multidisciplinary team care without a decrease in clinic volume;
- Maintain caregiver satisfaction rates with clinics during the transition to virtual visits and identify some aspects of care in which caregivers preferred virtual visits over in-person visits;
- Ensure team morale and mental health.

TABLE 1 Characteristics of survey respondents regarding virtual visits at the Massachusetts General Hospital Down Syndrome Program from April to September 2020

	N = 17	%
Respondent:		
Mother	11	65
Father	3	18
Other	3	18
Who attended the virtual visit?		
Patient	15	88
Mother	15	88
Father	6	35
Sibling(s)	2	12
Group home representative	1	6
How familiar were you with virtual visits before the one you had with the Massachusetts General Hospital Down Syndrome Program? Would you say you were...		
Very familiar	9	53
Somewhat familiar	5	29
Not at all aware of virtual visits, telemedicine, or similar services	3	18
When using technology, I feel:		
Very comfortable with using the technology and could begin a virtual visit on my own	12	71
Somewhat comfortable with using the technology and might be able to begin a virtual visit on my own	4	24
Somewhat comfortable with using the technology but would not be able to begin a virtual visit on my own	1	6
I can have a virtual visit in:		
A private location which is always available at any time	16	100
Where were you during your most recent virtual visit?		
At home	15	88
Other	2	12
What device did you use for your most recent virtual visit?		
Laptop computer	14	82
Smartphone	2	12
Desktop computer	1	6
What operating system does your device use?		
Windows operating system	11	65
Apple-Macintosh operating system	4	24
IOS (iPhone or iPad)	1	6
Android (android tablet or smartphone)	1	6
What method did you use to connect to the internet for your most recent virtual visit?		
Wireless connection over Wifi	14	82
Cable or broadband (wired)	2	12
Wireless connection over cell phone	1	6
	Mean	SD
Patient age (years)	19.4	11.8

The transition to virtual clinic workflow presented some challenges. Guidelines restricting our nutritionist from having visits with out-of-state patients based on licensing prohibited a full video visit; this was addressed with a telephone check-in, though a video visit would have been ideal. Some of our multidisciplinary services just cannot be done over videoconference, such as audiology, ophthalmology, and dentistry. Patients still needed blood work; thus, some in-person add-on visits were needed even if our MGH DSP was virtual. At the time of our transition to virtual visits, the Epic-integrated Zoom function was not yet configured for multidisciplinary groups like ours, so there is extra administrative work on all team members to implement the stand-alone Zoom functioning.

However, the transition to a virtual clinic workflow was also found to have advantages. We were able to keep our patients, families, and team members safe by decreasing risk of exposure to SARS-CoV-2 virus. We were also able to provide uninterrupted consultations to our families, many of whom have waited nearly 1 year for the appointment; canceling the appointments would have led to wait times of an additional year for next availability. In continuing our multidisciplinary model in virtual workflow, families still received timely consultations from our physicians, nutritionists, social workers, physical therapists, occupational therapists, speech therapists, and feeding therapists. The MGH DSP self-advocate resource specialist sent personalized follow-up to our families. We were able to complete guardianship evaluations, including neuropsychological assessments from the MGH Psychological Assessment Center. Our team was also able to achieve all original RVU goals.

During our first 6 months of virtual clinic, we found that our clinic metrics were not negatively impacted. We maintained the number of clinic visits, and we did not have a significant change in wait time to schedule appointments. Caregiver survey was positive for our overall clinic experience, and did not differ from pre-COVID scores. Telemedicine survey results showed that most caregivers were equipped for and comfortable with virtual video visits; all caregivers prefer virtual visits on travel time to visit. Caregivers preferred in-person visits for the personal connection they felt with the clinician, and in overall quality of the visit, some preferred in-person visit, but many felt it did not differ between virtual and in-person visit.

From team discussion, some additional themes emerged. First, the virtual visit can provide an intimate peek into both patient and clinician life. To address this, our team created a virtual background which some clinicians used for privacy and to prevent aspects of their home setting being seen in the background. Patients were also in their home setting, but this was viewed by some team members as positive; being at home made some patients more comfortable to engage in the visit, or to show aspects of personality that might not have come across during a regular visit. The safety of a patient's surroundings, such as one caregiver of an infant with DS conducting the visit from a car, was a new concept which would not have been present during an in-office visit. In that situation, additional outreach from social work and follow-up was completed to reinforce car seat safety for infants, to identify and communicate with the primary care physician, and to provide ongoing support to the caregiver.

TABLE 2 Feedback for virtual visits to the Massachusetts General Hospital Down Syndrome Program from April to September 2020

	N = 17	%	
Before your first Massachusetts General Hospital Down Syndrome Program virtual visit, did you receive information about how to access Zoom?			
Yes	15	88	
If yes, how helpful was the information you received?			
Very helpful	11	65	
Somewhat helpful	4	24	
Did you make a test Zoom call before your first virtual visit?			
Yes	3	18	
Did you access Zoom yourself or did someone help you?			
I accessed Zoom myself	16	94	
An MGH employee helped me access Zoom	1	6	
How difficult was it to access Zoom?			
Not at all difficult	13	76	
Not very difficult	3	18	
Somewhat difficult	1	6	
During your most recent virtual visit, did you have any problems with...	Yes, definitely	Yes, somewhat	No
1) Logging into the software			17
2) Joining the visit	1		16
3) Remaining connected during the visit		1	16
4) Sound (hearing or being heard)			17
5) Video (seeing or being seen)	1		16
6) Ending the visit			17
Did you have any other technical problems during your most recent virtual visit?			17
Thinking about your most recent virtual visit, please tell us how much you agree with the following items:			
1) I saw my clinician within 15 minutes of my appointment time	16	1	
2) My clinician explained things in a way that were easy to understand.	16		
3) My clinician listened carefully to me.	16	1	
4) My clinician spent enough time with me.	13	2	
Do you think the health issues discussed at your most recent virtual visit could have been managed as effectively by:			
1) A telephone call with my clinician	3	7	7
2) A secure private email exchange with my clinician	4	4	9
3) Exchanging text messages with my clinician	3	3	11
4) Completing a detailed questionnaire sent by my clinician	2	5	10
5) A traditional office visit	15	2	
Would you recommend this clinician to your family and friends?	16		

TABLE 2 (Continued)

	N = 17	%	
In the future, would you request a virtual visit if you had to pay...			
1) The full cost of the clinician visit	6	3	7
2) Half of the cost of the clinician visit	6	5	5
3) A co-payment of more than \$50	5	3	8
4) A co-payment of \$26–\$50	7	3	6
5) A co-payment of \$10–\$25	9	3	4
Would you recommend a virtual visit to your family and friends?	14	2	1
	Mean		
Using any number 0–10, where 0 is the WORST visit and 10 is the BEST visit, what number would you rate your virtual visit?	9.41		
What is your current co-payment for an in-person office visit?	\$37.14		
In general, how long does it take you to travel to MGH for office visits?	104 min		
In general, how much do you spend to travel to MGH for office visits (include tolls, parking, public transportation but NOT co-payments)	\$103.60		

Note: Bold = mode response to each item.

TABLE 3 Parent survey responses comparing video virtual visits to in-person office visits in the MGH Down Syndrome Program from April to September 2020

In general, tell us if a virtual visit is better, an office visit is better or there is no difference?	Response (N)			
	Virtual visit is better	No difference	Office visit is better	Does not matter
Finding a convenient time for the visit	10	5	2	–
Making arrangements for children or elders I care for	10	5	1	1
Travel time to the visit	16	1	–	–
Interruptions during the visit	3	10	3	1
The cost of the visit	5	7	–	3
Coordinating the visit	8	7	1	–
Ability of the patient with DS to attend the visit	2	9	5	1
Ability of caregivers to attend the visit	5	9	1	2
The amount of time that I wait for my clinician	9	6	1	1
The personal connection I feel with my clinician	1	5	10	1
The ability to show my clinician a physical problem	3	–	10	4
The comfort I feel sharing private or personal information	–	13	3	1
The confidence I feel that my health concern can be taken care of during the visit	3	9	4	1
The amount of time that I spend with my clinician	–	13	2	1
The overall quality of the visit	2	7	7	1

Note: Highlight = mode response to each item.

The role of a physical exam changed in a virtual visit. In some instances, additional history taking was needed to screen out for symptoms that would necessitate a physical exam, such as symptoms

of atlanto-axial instability with need for neurologic examination. Hypotonia is a common finding in DS and is not able to be assessed virtually; additional, more detailed questions were asked of caregivers.

TABLE 4 Team feedback on the transition to virtual visits: Lessons learned in themes and direct quotes

1) What has gone well in the transition to virtual visits?	
Accessibility	“Ease of access for team and for patients.”
	“Continued to provide medical care in multidisciplinary visits (MD, SW, RD)”
	“Able to have multiple parties present during the visits from different locations (DSP team, patient at group home with staff, and family at their home(s))”
	“Flexibility for team members to attend to school and family needs, while juggling work needs”
Improved discussion	“My internet connection is great and I have never lost service during Zoom, I feel I am doing a good job and able to connect with families well via zoom for the most part.”
	“Patients were able to use the virtual visit technology without major complications for the most part”
	Great for parent report and ideas/strategies based on their perception
	“More focused conversations with parents of younger kids who would otherwise be causing havoc in the exam rooms”
Efficiency	“Some families seem to be more open during virtual visits”
	“I think that huddle is working even better, as everyone has access to a computer, and their own computer.”
	“Being able to see some of the home environment for strategies on how to help in the child's own environment.”
	“I think that note writing is better, as I can see patients, type, and work on my note at the same time, whereas this was more awkward during the in-person visits based on the placement of the computers”
	“Zoom huddles are really efficient”
	“Being able to text a coordinator—For example, if a patient is late to our Zoom visit, we can text the clinic coordinator to check if the patient is still with another clinician or if the patient needs to be called to remind them about their appointment- it means less wasted time”
2) What challenges have arisen in the transition to virtual visits?	
Limited assessment	“It is hard to formally assess patients for developmental aspects, while some components (movement/speech/sensory needs/fine motor) are mostly report.”
	“In some cases, a physical examination would have been helpful (for example, to evaluate for undescended testicles: Have they changed since last visit?)”
Missing in-person components	“Unable to obtain vital signs. We do not have heights and weights, which makes an assessment for obesity/overweight, common in our population, challenging.”
	“Patients do not benefit from having audiology, ophthalmology, and dental on the same day and must come at different days for those visits.”
	Communication – “We lose the quick updates between provider-to-provider between patients in the team room and in the halls.”
	“When I would like to directly contact another clinician to give them information from my session with the patient; currently I text the coordinator to pass on the message but it would be better to communicate directly.”
	Patient-centered care- “Some individuals with Down syndrome appear to do well with video and some do not. It's hard to tell until we get into the visit what this looks like.”
	“Individuals with Down syndrome do not seem to participate as much in their care when virtual, and the family tends to speak for them more.”
	Time – “There really is not enough time to try and talk to parents and get the child on the video for 3 disciplines in 1 hour.”
Technology	“Unable to perform physical exam”
	“Unable to easily send patient to have labs drawn”
	“Some technology glitches (inevitable) such as freezing screens during virtual visits”
	“Some challenges with personal internet conductivity on my end, and some families seem to experience this, too. At times, there are families with ‘choppy’ internet access and it makes the visit more challenging. We have a good back up plan with the phone option, but it's always easier to virtually see the patient / family for ease of communication, non-verbal communication, visual examination, etc.”
	“Some families seem to need more support around accessing zoom ahead of time.”
	“It's hard to get a sense of the totality of a situation when we can only ‘see’ patients by phone, if video is unavailable or not able to be accessed. I tend to talk over the family or physician when I cannot see what is going on.”

TABLE 4 (Continued)

3) What lessons have you / we learned through this process?	
Telemedicine	<p>“Telemedicine works even better for some patients: Younger kids who can play while parents talk, out-of-state patients who do not want to travel, established patients who do not need a physical exam, patients who have a hard time during visits (ASD + DS patients), families who have several caregivers calling in from different places”</p> <p>“How to engage via video, assessment techniques without hands on manipulation and using the parents/caregivers to assist.”</p> <p>“A lot of great care can be provided virtually”</p> <p>“Need to figure out a way to get object vital signs for our patients who it may be decided staying with a virtual platform makes the most sense”</p> <p>“I think care will look different moving forward. This pandemic has taught me so many things re: Care and all the layers we need to consider. I definitely think how we deliver care needs to be re-examined, and I believe that there is value in virtual and in person – it's not a ‘one size fits all’. From a social work standpoint, I have seen how virtual visits can help families who may experience barriers to care (transportation, financial barriers, parking, time off from work, etc) access equitable care. On the flip side, seeing and evaluating in person is still the ‘gold standard’ for me in most circumstances. I do not see as much self-advocacy and input from the person with DS virtually.”</p> <p>“I think from the administrative side, in adapting to virtual visits, we learned that offering practice sessions with those families particularly new to technology eased their hesitation and helped with a successful outcome.”</p> <p>“Use of the HelpDesk”</p> <p>“Charting during a visit may be difficult if there are multiple people attending a session.”</p> <p>“If we move forward with delivering care in a hybrid model, our team would need to come up with parameters for those seen virtually vs. in person. This may be complicated based on multiple factors, but I think we could come up with a good plan.”</p> <p>“Zoom brings work life (clinic) into a clinician's home which can impact work-life balance and give patients a view into home / private life”</p> <p>“Safety of a patient's surroundings, for example, one parent conducted the visit from a car, was a new concept which would not have been present during an in-office visit. “</p>
Team	<p>“It is still vital to maintain a group dynamic: Monday meetings, team huddles, and team lunches are essential to feeling a team bond, which translates into better care”</p> <p>“Providers may continue to need flexibility with parenting, school, and work, so this also needs to be considered in the big picture. I would like to see more of a model of some in-person and work from home options.”</p> <p>“I am so proud of how our team has risen to the occasion, and I feel that I can be open about my work and life responsibilities, but we have room to grow with learning more about how we can support staff with all that they are juggling. Sometimes, we just forge ahead without talking as a team, and I do not think we always have the chance to share what we are worried about in a more regular forum. Mondays are great for checking in, but there is more under the surface that we may keep to ourselves or share with a few people, and if we had the forum, we would likely see that many of us are struggling with the same things.”</p> <p>“We need to build a 5 minute break in-between visits (the time that we usually wrap up the in-person visits, stand up, switch rooms, etc). This opportunity to stretch our legs does not exist with virtual visits, and we can spend 4 straight hours sitting down in front of a screen, which is not healthy for providers.”</p>
Communication	<p>“During times of crisis (such as this pandemic), it is important to stay in touch. I think our e-newsletters were important and well-received by patients and families during the height of the crisis.”</p>

The American Academy of Pediatrics suggests that we evaluate for neurologic symptoms, but this was not possible in the virtual visit (Bull & Committee on Genetics, 2011). Obtaining objective vital signs consistently was a challenge. Other situations which would have benefitted from a physical exam included evaluation of a gastrostomy tube site, evaluation for dermatologic conditions, undescended testicles, and evaluation of tonsil size. In our virtual visit transition, we had the option to petition our department to have an in-person clinic visit for a patient if needed, so in the transition, physicians were often assessing if any patient needed to be scheduled for in-person visit in MGH DSP, referred for an outpatient visit with the primary care physician, or referred to the emergency department.

We found that we were weighing the risks and benefits of an in-person visit to those of a virtual video visit. For example, for some of our out-of-state patients, a virtual visit would ease the travel to Boston, but out-of-state patients may not have had access to nutrition services. For many of our patients, during the COVID-19 pandemic, it was more beneficial to conduct visits virtually and minimize the risk of infection. As COVID-19 infection rates change, we will be interested to see how this factors into the decision. We have seen positive aspects of transitioning to a virtual visit workflow, and we suspect that some families may prefer this model even after the COVID-19 pandemic has passed. Future study will be useful to determine if our success in virtual visits is sustained.

Additionally, in the future we would like to monitor the transition on diverse groups given the racial and ethnic disparities in COVID-19 impact. We did not collect this information, which limits our ability to assess this in the current study. Our survey was sent to all 211 caregivers who had a virtual visit but were only completed by 17; a response rate of 8% implies that many of our caregivers either did not want to or were unable to give feedback through the electronic survey. We would like to increase the number of responses we receive but suspect that some caregivers may not complete the survey if they are generally satisfied with the experience, that some caregivers may have digital overload, and have found that this response rate is similar to our baseline response rate prior to COVID. The survey was adapted from a validated survey, and assessed for face validity, but not validated in the DS population prior to distribution. Other limitations include this is retrospective information collected during our six-month transition period and is limited by the information available.

These results may not generalize to all DS clinics or to all multidisciplinary clinics, and may not apply to other locations based on local regulations or hospital policies. For clinics which are transitioning to virtual clinic, but may not have the infrastructure outlined, modifications may be needed such as: decreasing the number of disciplines in a visit, or limiting the number of patients seen when initially starting up, or making use of existing clinic workflows and support. In an environment with lower resources, it would be more expensive to replicate the multidisciplinary clinic in-person than a virtual clinic. And, in a lower resource environment, barriers such as identifying specialists in the environment could be overcome through the use of virtual technology. The virtual visit model might allow specialists in different departments, different facilities, and different hospital systems to work together, even if not in the same geographic location. The MGH DSP model may not apply to all multidisciplinary clinics, but use of virtual visits allows others to observe the MGH DSP clinic to identify which aspects of the clinic model could translate to their situation.

5 | CONCLUSION

The COVID-19 pandemic necessitated a rapid transition to virtual visits in the Down Syndrome Program at MGH, but we were able to maintain multidisciplinary, specialty care with optimal caregiver feedback and sustained number of patients seen. Through our transition to virtual visits, we learned lessons on balancing the use of telemedicine, which can improve accessibility and discussion, but may also lack some features and limit clinical assessments.

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CONFLICT OF INTEREST

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. Dr. Skotko receives annual royalties from Woodbine House, Inc., for the publication of his book, *Fasten Your Seatbelt: A Crash Course on DS for Brothers and Sisters*. Within the past two years, he has received research funding from F. Hoffmann-La Roche, Inc., 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. Dr. Skotko has a sister with Down syndrome.

Dr. Santoro receives research funding from the LuMind IDSC Down Syndrome Foundation to conduct clinical trials for people with DS and serves on the Professional Advisory Board for the Massachusetts Down Syndrome Congress. The other authors have no conflicts of interest relevant to this article to disclose.

AUTHOR CONTRIBUTIONS

All authors confirm that this article has not been published previously and is not under consideration elsewhere, that all authors are responsible for reported research, and that all authors have participated in the concept and design, analysis and interpretation of data, drafting or revising of the article, and have read and approved the submission to the journal. We look forward to your feedback and review of this article.

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 restrictions, as sharing of responses was not disclosed prior to survey completion.

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