Tele-Clinic Visits in Pediatric Patients with Marfan Syndrome Using Parentally Acquired Echocardiography

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Objective To test feasibility of tele-clinic visits using parentally acquired vital signs and focused echocardiographic images in patients with Marfan syndrome.

Study design We included patients with Marfan syndrome aged 5-19 years followed in our clinic. We excluded patients with Marfan syndrome and history of previous aortic root (AoR) surgery, cardiomyopathy, arrhythmia, or AoR ≥4.5 cm. We trained parents in-person to acquire focused echocardiographic images on their children using a hand-held device as well as how to use a stadiometer, scale, blood pressure (BP) machine, and a digital stethoscope. Before tele-clinic visits, parents obtained the echocardiographic images and vital signs. We compared tele-clinic and on-site clinic visit data. Parental and clinic echocardiograms were independently analyzed.

Results Fifteen patient/parent pairs completed tele-clinic visits, conducted at a median of 7.0 (IQR 3.0-9.9) months from the in-person training session. Parents took a median of 70 (IQR 60-150) minutes to obtain the height, weight, heart rate, BP, cardiac sounds, and echocardiographic images before tele-clinic visits. Systolic BP was greater on-site than at home (median +13 mm Hg, $P = .014$). Height, weight, diastolic BP, heart rate, and AoR measurements were similar.

Conclusions This study provides information for implementing tele-clinic visits using parentally acquired vital signs and echocardiographic images in patients with Marfan syndrome. The results show that tele-clinic visits are feasible and that parents were able to obtain focused echocardiographic images on their children. *(J Pediatr 2021;232:140-6)*.

Trial Registration ClinicalTrials.gov: NCT03581682.

Marfan syndrome is a connective tissue disorder caused by mutations in the gene encoding fibrillin-1 and affects multiple organ systems.[1] Patients with Marfan syndrome are at risk for progressive aortic root (AoR) dilation, which can lead to aortic dissection and sudden death.[2,3] Current clinical guidelines recommend clinic visits with an echocardiography performed every 6-12 months to monitor the AoR.[4] Elective surgery is performed when AoR diameter or dilation rate reach established criteria.[5] Fortunately, AoR monitoring and prophylactic AoR surgery have been effective. The median life expectancy of patients with Marfan syndrome has increased from only 32 years[6] to near to that of the general population.[7] Because many patients with Marfan syndrome live far away from specialized centers, the current model of care with frequent clinic visits represents a significant burden. In our center, our patients reside up to 700 miles away, incurring significant monetary and time costs for routine screening.

Technology has allowed for increased use of tele-visits in pediatrics in the last decade. Examples include addressing medication nonadherence in diabetes or asthma care, providing lifestyle coaching and monitoring for patients with obesity, improving access for specialty consultation for patients in remote emergency departments, and administering counseling for mental health treatment.[8-10] Furthermore, hand-held echocardiographic devices have been an important component of technology that can address the issue of distance to specialized centers. These devices have typically been used to train medical personnel and to triage sick patients in clinical settings.[11] Our team has shown that it is feasible to train parents of patients undergoing heart transplant to obtain echocardiograms at home for reliable assessment of left ventricular systolic function.[12]

In addition, it is known that parents of children with chronic illness have limited choices in the care of their children.[13] At the same time, studies have shown that increased collaboration between parents and the care team improves outcomes.[14] The goal of the study was to evaluate whether a tele-clinic visit using

AoR	Aortic root
BP	Blood pressure
CAHPS	Consumer Assessment of Healthcare Providers and Systems

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parentally obtained echocardiography is feasible and whether these focused images obtained by the parents at home are of adequate quality for AoR measurements.

Methods

We purchased all the necessary equipment to conduct this pilot tele-clinic study using the funds provided by the Stanford Maternal & Child Health Research Institute Faculty Scholarship Award. Pediatric patients with Marfan syndrome and their parents were recruited from the Cardiovascular Connective Tissue Disorder Clinic at Lucile Packard Children's Hospital Stanford. Subjects were eligible to participate if they met all of the following inclusion criteria: Marfan syndrome by revised Ghent criteria; 5-19 years of age; and 1 previous visit in our clinic. Subjects were excluded if they had AoR surgery previously; known cardiomyopathy; known arrhythmia; and AoR dimension >4.5 cm reported in the most recent clinic visit.

We reviewed the Cardiovascular Connective Tissue Disorder Clinic roster at our institution for eligible participants. After approval from their cardiologist, we approached the patients either in clinic or via opt-in recruitment packages sent by mail. All study-related procedures and materials were approved by the Stanford institutional review board. Before participating in any study-related activities, all parents signed consent forms as adult participants as well as an additional consent form on behalf of their children if younger than the age of 18 years. Patients aged 7-17 years signed assent forms to confirm their understanding of participation in the study.

Parents participated in a hands-on in-person training session in clinic to learn how to acquire focused echocardiographic images on their children using a hand-held device in addition to how to obtain vital signs. We scheduled in-person training sessions on the same day as a previously scheduled clinic visit, if possible, to reduce familial burden. Some participants traveled to our center specifically to complete the training.

The parent and patient pairs first met with the study coordinator who reviewed the use of the medically validated scale (Seca Aura 807), stadiometer (Seca 213), oscillometric blood pressure (BP) machine (Omron 5 Series), and digital stethoscope (3M) (Figure 1). Parents were instructed on how to measure or record their children's height, weight, BP, heart rate, and heart sounds using these devices. Next, the study coordinator reviewed basic tablet (Samsung Galaxy) controls as well as patient and probe (Phillips Lumify) positioning using a training manual created for parents to follow along. This training manual also included in-depth, step-by-step instructions on how to collect and upload all data (Figure 1). Parents were then asked to review a training video before hands-on training to obtain a basic

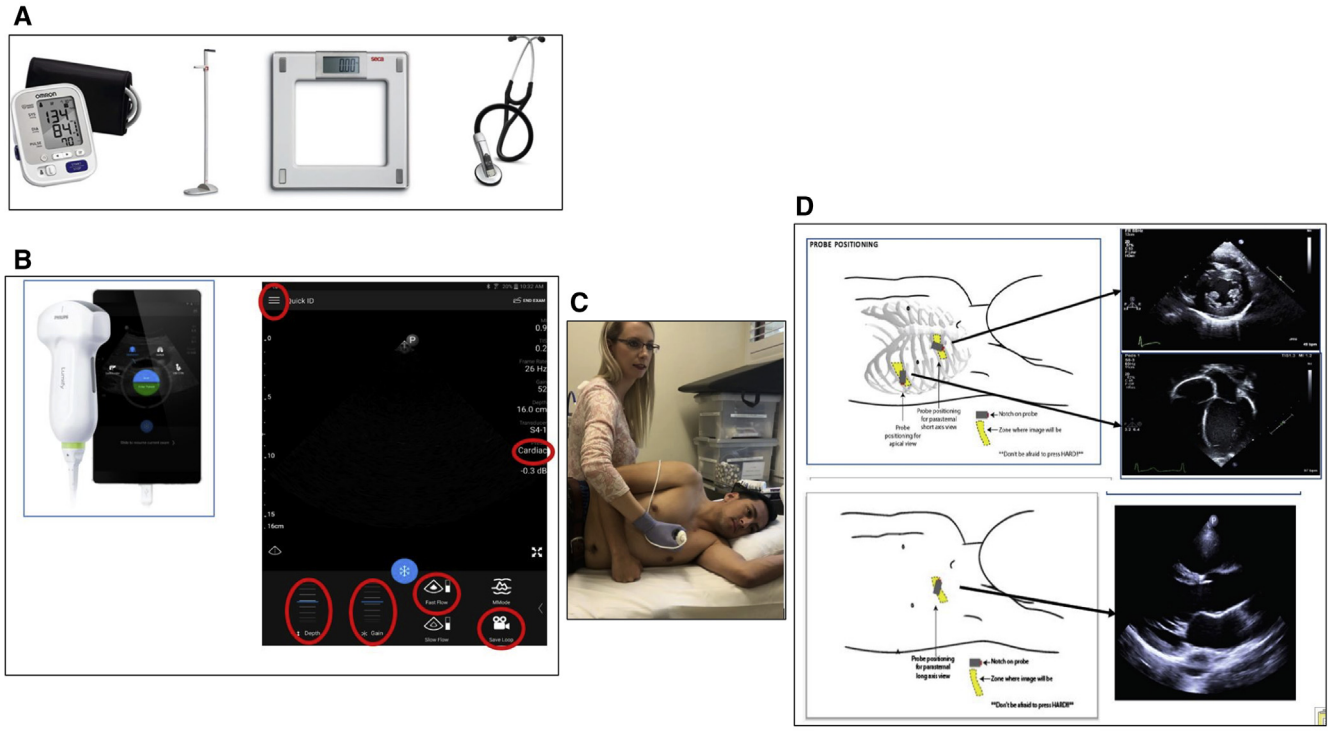

Figure 1. Training material and equipment for the Marfan tele-clinic. **A,** BP machine, stadiometer, scale, and digital stethoscope for measurement of vitals at home. **B,** Hand-held echocardiographic device and tablet screen controls. **C,** Training video to serve as a refresher. **D,** Training documents for patient and probe positioning and image acquisition for in-person training.

understanding of the focused echocardiographic imaging they will learn (Figure 1).

Upon completion of the aforementioned tasks, parents received hands-on training by an attending echocardiographer faculty or a senior sonographer on how to acquire basic echocardiographic images in 3 planes—the parasternal long axis, parasternal short axis, and apical 4-chamber—to visualize the AoR, aortic and mitral valves, and to assess left ventricular systolic function. They were instructed how to use 2-dimensional and color Doppler. Parents were required to demonstrate their ability by taking 5 clips on their own in each plane before training was completed.

After completion of the hands-on training, parents completed surveys to gauge their initial Family Empowerment Scale score[15] as well as time, opportunity, and financial costs of traveling to clinic. Parent/patient pairs were given the scale, stadiometer, and BP machine to take home and keep after completion of the training visit. All participants were also given a $25 Amazon gift card and parking vouchers.

After the initial training visit, the study coordinator mailed all additional supplies to the study participants' homes, including the tablet (for the echocardiographic imaging), ultrasound probe, laptop for the video-conferencing (Microsoft), stethoscope, gel, and training manual. The same echocardiographic training video viewed at training (Figure 1) was uploaded to the laptop for the parents to review before imaging. All parents were instructed to review the video before any image acquisition and to contact the study team if they had any questions before the at-home data acquisition.

Any parent/patient pairs scheduled to participate in the tele-clinic more than 3 months from the initial training visit were given the opportunity to re-train via live-video conferencing with a senior sonographer prior to their tele-clinic visit if they opted to.

As per study protocol, patients acquired and recorded their children's height, weight, BP, pulse, heart sounds, and echocardiographic images before the tele-clinic using the training manual as a reference (Figure 1), which ensured that any technical troubleshooting could be completed ahead of time. Cardiac sounds were acquired via the digital stethoscope and uploaded onto the Littman 3M on the provided study laptop software. Deidentified echocardiographic images were exported directly from the tablet to our center's imaging platform (Siemens Medical Solutions USA, Inc; syngoDynamics Solutions) for the study team to access remotely.

Tele-clinic visits were scheduled at a convenient time for the patients/parents after the initial training visit. All tele-clinic visits were completed over VSee, video-conferencing platform compliant with the Health Insurance Portability and Accountability Act of 1996 that was preloaded on the study laptop provided to the parents/patient pairs. Before the tele-clinic visit, the study coordinator verified that all materials were ready and that there were no technical difficulties. The Marfan syndrome clinic provider reviewed the parentally acquired images and made AoR measurements. Then, the Marfan syndrome clinic provider administered the tele-visit by reviewing the patient's medical history and anthropometric measurements, listening to digital heart sounds played over the speaker on the laptop, reviewing the parentally acquired echocardiographic images, and addressing any concerns from the parents/patient pairs. Final assessments of the patient were not shared with the parent/patient pairs to reduce bias at the upcoming clinic visit and to prevent the possibility of patients skipping their on-site clinic visits. The study team emphasized that the tele-clinic visits were completed for research purposes only and not intended for replacement of medical advice in formal clinical settings.

The patients attended their regularly scheduled on-site clinic visits. Although the on-site clinic visits were initially intended to occur after the tele-clinic visit, sometimes they occurred in advance, due to timing or scheduling conflicts. After completion of the on-site clinic visits, both patients and parents were asked to complete questionnaires on their experience in the study. Participants were also given a $50 Amazon gift card at the study end completion.

To evaluate the feasibility and reliability of the tele-clinic visits, we compared data collected during the tele-clinic with data collected at the most temporally proximate (whether before or after) on-site clinic visit. In addition, we considered the time-cost of implementing tele-clinic visits vs on-site clinic visits for patients.

We compared all study measures from tele-clinic visit with the paired clinic visits. The parental tele-clinic echocardiograms and on-site clinic echocardiograms were independently reviewed and analyzed by a blinded echocardiographer (faculty). Three measurements were made in systole with the inner-edge-to-inner edge technique as per laboratory protocol and averaged. Z scores for each echocardiogram were determined for additional comparison. Z scores for all AoR measurements were calculated using Boston Children's Hospital's z-score website (http://zscore.chboston.org). Tele-clinic z scores were determined using height, weight, age, and AoR measurement from the tele-clinic and on-site clinic z scores were determined using height, weight, age, and aortic measurement from the on-site clinic.

We also included time variables into our analysis. An important consideration for the feasibility of tele-clinic visits is if this clinic format saves patients and/or physicians time while maintaining high clinical accuracy. Time variables that were considered part of tele-clinic visits were patient travel time to attend the in-person training session, time in training, time to acquire tele-clinic data at home, and time in tele-clinic. This was compared with time spent traveling to an on-site clinic visit and time in clinic. Travel time was calculated using Google Maps directions for travel between the participants' homes and our center for an arrival time of noon on an average Monday.

Study team time was defined as time spent training parents at each in-person training session and time spent

administering clinic visits. Assessment of parent and patient time costs was conducted through surveys, self-reports, and standardized travel-time by distance using Google Maps directions. Equipment costs included items that were provided to the study participants at the initial in-person training session or shipped to them before the tele-clinic.

Parents were asked to complete the Family Empowerment Scale questionnaire at training and after the tele-clinic visits for evaluation of whether the study improved parental sense of empowerment. The questionnaire is separated into 3 subsections of family, services, and community, and includes a total of 34 validated questions. Each question is scored from 1 to 5. The total score ranges from 34 to 170. A greater number indicates higher sense of empowerment.[15] Parents were also instructed to complete the Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey, a validated survey designed to assess patients' clinical experiences with healthcare providers and hospital staff, after their on-site clinic visit and a feedback survey after the tele-clinic visit for evaluation of any differences in patient-parent experiences for each visit.[16]

Wilcoxon signed rank test was used for paired comparisons between the tele-clinic and on-site clinic data measurements for each patient. The median and IQRs were calculated. Percent difference for all values were calculated as the absolute value of (value on-site clinic–value tele-clinic)/[{value on-site clinic + value tele-clinic}/2]). Changes in median were calculated as value on-site clinic–value tele-clinic. Statistical analysis was performed using SPSS Statistics (IBM Corp). Statistical significance was defined at $P < .05$.

Results

Eighteen patients (11 male) with Marfan syndrome and 18 parents (9 male) were enrolled and completed training. Patients were a median age of 9.8 (IRQ 7.5-15.3) years at initial training and lived a median distance of 56.6 (IRQ 32.3-203.8) miles from our center. The median yearly income by zip code was $82 010 (IQR $54 024-$146 498).

Ten additional patient/parent pairs were approached for enrollment in the study and declined. These 10 patients were a median age of 14 (IQR 10.0-15.7) years, lived a median of 104 (IQR 46-165) miles from our center, and had a median household income by ZIP code of $78 760 (IQR $60 323-$87 688).

Parents took a median of 0.5 (IQR 0.00-1.00) days off work, and patients took a median of 1.00 (IQR 0.00-1.00) days off school to attend the in-person training session. Total in-person training time was a median of 83 (IQR 75.0-94.3) minutes. Total time for travel (round trip) for patient and parents was a median of 145 (IQR 99-458) minutes.

Overall, 15 patient/parent pairs completed the tele-clinic visits, which were scheduled a median of 0.54 (IQR 0.19-0.83) years from the initial in-person training session. The participants had the following time intervals: 9 of 15 patients were seen in both visits in a time interval of less than 1 month, 2 of 15 were seen in an interval of less than 3 months, 2 of the 15 were seen in a time interval of less than 9 months, and 2 of 15 were seen in a time interval between 9 and 18 months.

Data acquisition for the tele-clinic visits took parents a median of 70 (IQR 60-150) minutes. Total time in the tele-clinic visits lasted a duration of 38 (IQR 30-45) minutes. Time spent with the Marfan syndrome clinic provider lasted a median of 12 (IQR 15-19) minutes. Three patient/parent pairs did not complete the study after participating in the in-person training session because 2 of these patient/parent pairs were lost to follow-up and 1 patient/parent declined to return due to additional medical issues not related to Marfan syndrome.

All 15 parents who completed tele-clinic visits were successful in obtaining all required study data. Time between the tele-clinic and the on-site clinic visits was a median of 0.23 (IQR 0.1-3.1) months.

Comparing parentally obtained data with results obtained in the on-site clinic by medical professionals, we found there were no statistically significant differences in height (median −2 cm, $P = .44$), weight (median −1.3 kg, $P = .14$), diastolic BP (median −2 mm Hg, $P = .64$), or heart rate (median +3 beats per minute, $P = .18$). The difference in systolic BP was statistically significant (median +13 mm Hg, $P = .01$) between the tele-clinic and clinic data comparisons. Median percent differences were 1.1% (height), 1.9% (weight), 9.9% (pulse), 9.4% (systolic BP), and 10% (diastolic BP).

AoR measurements on the parentally acquired tele-clinic echocardiograms (median 2.89 [IQR 2.72-3.14] cm) compared with on-site clinical echocardiograms (median 2.98 [IQR 2.67-3.28] cm) were not different (median +0.09, $P = .63$) (**Figure 2**). The minimum difference between the absolute AoR measurements was 0.02 cm and the maximum difference was 0.24 cm. The percent difference in AoR measurements from tele-clinic and on-site clinic was a median of 3.4 % (IQR 1.8-6.7%) (**Table I**). The AoR z scores were also not statistically significantly different between the tele-clinic (median 2.71 [IQR 1.43-4.27]) and on-site clinic echocardiograms (median 2.35 [IQR 1.67-4.67]) (median −0.61, $P = .26$) (**Table II**).

The total amount of time spent for tele-clinic visits, including travel time for training, training time, time spent collecting tele-clinic data, and time in tele-clinic for patients and parents was a median of 395 (IQR 298-731) minutes. The total amount of time spent with each participant for training and the tele-clinic visit was a median of 119 (IQR 113-134) minutes. This total time does not include the initial study set up time.

The cost of equipment purchased for tele-clinic visits included the $8000 Lumify probe, $200 Samsung Galaxy tablet, $250 3M stethoscope, and $1000 laptop for video conferencing. The stadiometer, scale, and BP machine were $150, $50, and $35, respectively.

Family Empowerment Scale scores did not demonstrate any significant change from training to the tele-clinic visits (median +8, $P = .88$). The total score at training and

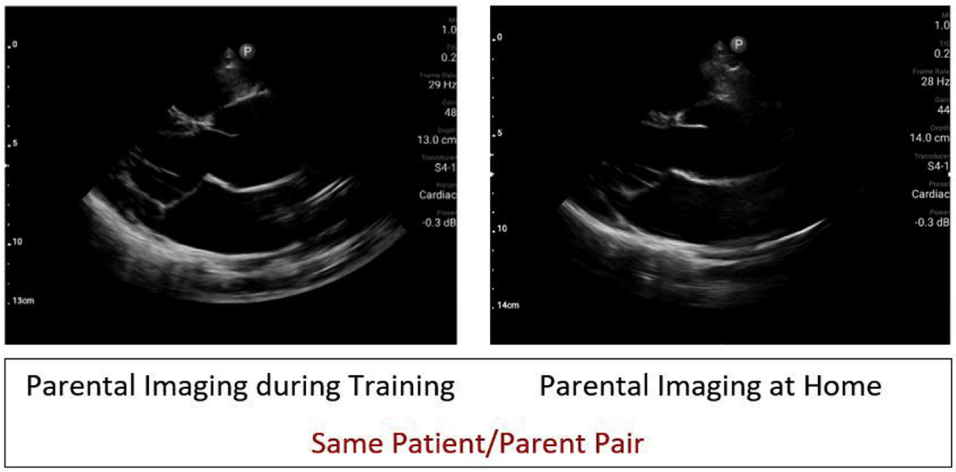

Figure 2. Example of parental training and home echocardiographic images.

tele-clinic was a median of 130.5 (IQR 122.3-146.5) and 138.5 (IQR 120.3-148.5), respectively.

In response to the CAHPS Clinician and Group Survey, all parents answered "yes" to the question "Is your child able to talk with providers about his/her healthcare?" and in response to the question "In the last 6 months, how often did this provider explain things in a way that was easy for your child to understand?" parents answered either "always" or "usually." All parents responded "yes" to the question "Did this provider give you enough information about what you needed to do to follow up on your child's care?" All responses from the question "Using any number from 0 to 10, where 0 is the worst provider possible and 10 is the best provider possible, what number would you use to rate this provider?" were between 8 and 10.

All parents reported feeling "moderately" or "very comfortable" imaging their children and believed that at-home clinic visits would be either "moderately" or "very useful." Four parents provided additional feedback on why their response was only "moderately comfortable or useful," elaborating that they "needed more practice as it was difficult to obtain good images" and that their child "had more difficulty staying still for the home echocardiogram compared with the one in clinic." One parent also reported that "We had a really great experience and enjoyed the ease of the appointment. I could see this being helpful and a way to make great care accessible to more people in the future and a way to simplify

Table I. AoR measurement comparison: tele-clinic vs on-site clinic

Patients	AoR measurement* on tele-clinic echocardiogram, parental, cm	AoR measurement on on-site clinic echocardiogram, cm	Percent difference (%)
1	3.10	3.17	2.2%
2	4.30	4.26	1.0%
3	2.90	3.00	3.6%
4	3.11	3.34	7.2%
5	3.16	3.21	1.6%
6	2.74	2.98	8.2%
7	2.54	2.50	1.7%
8	3.62	3.86	6.4%
9	2.89	2.79	3.4%
10	2.78	2.59	7.2%
11	2.66	2.79	4.9%
12	2.30	2.28	0.9%
13	2.70	2.54	6.1%
14	2.79	2.74	1.8%
15	3.81	3.74	1.9%
Median	2.89	2.98	3.4%
Q1	2.72	2.67	1.8%
Q3	3.14	3.28	6.7%

*Three measurements made in systole with the inner-edge-to-inner edge technique as per laboratory protocol and averaged.

Table II. AoR z-score comparison: tele-clinic (parental) vs on-site clinic echocardiograms

Patients	AoR z-score tele-clinic echocardiogram (parental)*	AoR z-score on-site clinic echocardiogram*
1	1.19	1.40
2	4.69	4.44
3	1.49	1.93
4	3.84	4.87
5	4.96	5.43
6	−0.83	0.21
7	2.71	2.94
8	5.17	6.31
9	1.33	1.18
10	2.64	2.00
11	3.78	4.46
12	1.36	1.20
13	3.09	2.24
14	2.46	2.35
15	6.74	6.43
Median	2.71	2.35
Q1	1.43	1.67
Q3	4.27	4.67

*Determined using Boston Children's Hospital z-score calculator and age, height, weight, and averaged AoR measurement.

appointments for routine check-ups." The general consensus for the study participants and their parents was that tele-clinic visits could potentially save a considerable amount of time as long as the accuracy and quality of care compared with that of a regular on-site clinic visit.

Discussion

This study provides information for implementing tele-clinic visits using parentally obtained echocardiograms in patients with Marfan syndrome. Our results demonstrated that tele-clinic visits are feasible and that parents are able to obtain focused echocardiographic images on their children that are adequate to assess the AoR dimension. Although most studies have widely used hand-held devices for focused echocardiography, imaging was completed by experienced sonographers, cardiology fellows/attendings, or noncardiologists such as hospitalists.[11,17,18]

The most important clinical data to monitor pediatric patients with Marfan syndrome is the AoR dimension. Our median difference for AoR measurement between parentally acquired tele-clinic echocardiograms and on-site clinic echocardiograms was 3.4%, which is comparable with what has been published in a large pediatric Marfan syndrome trial, where the primary outcome was the rate of change of the AoR.[19] In a clinical setting, 5%-10% variability is anticipated and acceptable, given that image acquisition and analyses are performed by different providers at different times.

There were no significant differences in the quantitative data acquired, except for the systolic BP, which was a median of 13 mm Hg greater at the on-site clinic visit. One potential explanation of this result is white-coat-hypertension.[20] Other explanations include timing of the BP measurement during the day or use of a different cuff size. One might consider mitigating this issue by obtaining multiple BP in each setting and averaging these values.

Family Empowerment Scale scores showed no significant change in parental empowerment from training to tele-clinic. This could be explained by our observation that some parents believed they needed more training before obtaining reliable echocardiographic images on their child. Median Family Empowerment Scale scores at tele-clinic and clinic were 130.5 and 138.5, respectively, of a total score of 170, indicating that at baseline, parents of pediatric patients with Marfan syndrome at our site already had a high sense of empowerment.

Results from the CAHPS Clinician and Group Survey and the Tele-Clinic Survey indicated a high level of satisfaction for both on-site clinic and tele-clinic visits as responses were all in the top categories. Although a direct, quantitative comparison is not possible due to different surveys and the qualitative nature of the data, it is reasonable to conclude that participants felt like they had adequate, comfortable, professional care in both visits. We had chosen to use 2 surveys because CAHPS focuses its evaluation on parent satisfaction of the provider and other staff involved in their child's care, but not necessarily on the delivery method of the care (on-site). By using a separate survey for tele-clinic, we were able to ask targeted questions about the novel use of parentally obtained echocardiograms and live-video conferencing to evaluate patient/parent satisfaction of the tele-clinic visits.

We also sought to evaluate whether tele-clinic visits could save patient/parent pairs time compared with on-site clinic visits due to the travel time saved. Our results showed that patients and their parents traveled a median of 120 (IRQ 103-495) minutes roundtrip to training but that travel time would be very similar for the time it takes to attend a regular on-site clinic visit. As parents improve their imaging technique and become more comfortable with image acquisition, training time would diminish, and the only time spent on tele-clinic visits would be for data acquisition and the tele-clinic visit itself. Whereas time spend on regular on-site clinic visits would remain the same with travel and time spent at on-site in clinic. The cost associated with the purchase of the advanced devices used in this study including the hand-held echocardiographic device and digital stethoscope could be a limitation in some centers.

There were some technical limitations to our study that we had to work around and with during the study period. For this study, we developed a system to allow for direct echocardiographic image upload from the tablet to our informatics platform (Siemens Medical Solutions USA, Inc; syngoDynamics Solutions); however, the transmission was not always seamless. Sometimes there were issues with the technology itself and other times user error prevented successful transmission. In addition, the digital stethoscope chosen for this project required importing the sound files to proprietary Littman software on a computer and did not yield clear sounds when played on the speaker for the physician over live-video conferencing. Although the issues were often resolved over the phone with the study team, these technical encounters are usually not present during in-person clinic visits, although are likely becoming more common with increasing use of telehealth in the coronavirus disease 2019 era.

In addition, we could not standardize the time between the initial in-person training session and the subsequent tele-clinic and on-site clinic visits. As we did not want to influence the timing of clinic visits, which were often canceled, rescheduled, or scheduled last-minute, we could only attempt to schedule the tele-clinic visits within a reasonable time frame for comparison. The challenges with the timing of tele-clinic visits include the possibility that some parents may have had a better recollection of the training due to less time elapsed between the visits and thus handled the echocardiographic imaging better. The maximum time interval between a tele-clinic visit and on-site clinic visit we have is 18 months, but that parent was able to obtain adequate images for assessment, nevertheless. Most of the time intervals should not result in significant change in clinical assessment, however, it still represents a limitation and a potential source of variability in our study.

Finally, selection bias could have influenced our results as patient/parent pairs who opted to participate may have been more motivated by the prospect of tele-clinic visits due to their distance to our center. However, the patient demographics for those who did not participate were not significantly different from the participants enrolled in the study. The difference in medians between the 2 groups for age was +4.2 years, $P = .21$, for distance to center was +47.0 miles, $P = .97$, and for household income was –$3340, $P = .75$.

Frequent training and communication between parents and the clinical team may be necessary to ensure that home imaging quality remain adequate over time. The results of this study come at an important time as coronavirus disease 2019 has changed the landscape of how care for non-critical patients is provided. We have observed a shift towards telehealth in recent months and are optimistic that tele-clinics that involve a parental imaging component will be part of the future of healthcare. ■

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