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ARTICLE

Use of Patient-Specific "4D" Tele-Education to Enhance Actual and Perceived Knowledge in Congenital Heart Disease (CHD) Patients

Molly Clarke[1,*], Karin Hamann[2], Nancy Klein[2], Laura Olivieri[3] and Yue-Hin Loke[2]

[1]Department of Inpatient Cardiology, Boston Children's Hospital, Boston, 02115, USA

[2]Department of Cardiology, Children's National Hospital, Washington, 20001, USA

[3]Department of Cardiology, Noninvasive Cardiac Imaging, University of Pittsburgh Medical Center Children's Hospital of Pittsburgh, Pittsburgh, 15224, USA

[*]Corresponding Author: Molly Clarke. Email: molly.clarke@cardio.chboston.org

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ABSTRACT

Background: Patients with congenital heart disease (CHD) will transition to lifelong adult congenital cardiac care. However, their structural heart disease is challenging to convey via two-dimensional drawings. This study utilized a tele-educational environment, with personalized three-dimensional (3D) modeling and health Details (3D + Details = "4D"), to improve actual and perceived knowledge, both important components of transition readiness in CHD patients. **Methods:** Participants aged ≥13 years with a history of CHD and cardiac magnetic resonance imaging (MRI) studies were eligible. Cardiac MRI datasets were then used to segment and create 3D heart models (using Mimics, Materialize Inc.). Participants first completed the MyHeart Questionnaire, a validated survey of actual knowledge. A tele-educational session was then scheduled, during which participants were shown a 3D model of a normal heart, followed by their personal 3D heart model and specific health details. Participants then repeated the actual knowledge survey, in addition to questionnaires assessing perceived knowledge pre- and post-session, as well as a satisfaction survey. **Results:** Twenty-two patients were included. Actual knowledge increased from 75% ± 15% to 89% ± 20% (p = 0.00043) and perceived knowledge increased in five of seven questions. Actual knowledge correlated with perceived knowledge (r = 0.608, p < 0.0001). Ninety-one percent of participants ranked the 3D model as "very satisfactory" and ninety-five percent ranked the educational session as "very helpful" or "extremely helpful." **Conclusions:** The use of "4D" tele-education increased both actual and perceived knowledge and may help improve transition readiness in CHD patients.

KEYWORDS

Congenital heart disease; tele-education; transition

Nomenclature

CHD	Congenital Heart Disease
ACHD	Adult Congenital Heart Disease

1 Introduction

Pediatric patients with congenital heart disease (CHD) must transition to lifelong adult congenital cardiac care [1]. With more CHD patients surviving into adulthood [2], approximately 50% do not successfully transition to adult CHD (ACHD) care [3,4], which has a significant impact on long term mortality and morbidity. The most common reasons for failure include a general lack of overt symptoms and/or unclear guidance on reasons for long-term follow-up [4]. One key aspect to CHD transition readiness is a patients' knowledge of their heart disease, including a basic understanding of the cardiac anatomy and prior surgical interventions. Increased medical condition knowledge correlates with greater transition readiness [5,6], and other studies have addressed educational programs on knowledge and transition readiness as a whole [7–9].

Educational sessions utilizing patient-specific three-dimensional (3D) models offer the potential to enhance the overall educational experience for CHD patients. Traditionally, cardiologists have utilized two-dimensional (2D) imaging in the form of diagrams or still-frame images, which only partially present the cardiac anatomy. However, 2D imaging does not fully capture the unique anatomy for each individual, even for those with the same CHD diagnosis. Patient-specific 3D models have been used to enhance communication between providers and parents [10]. Our group and others have shown its efficacy for medical trainees [11,12] and patients [13]. Other strategies include educational sessions with individualized health professional-led didactics, videos, video games, and/or the use of ACHD "passports" [7–9,14,15] to succinctly summarize a patient's cardiac medical history, key vital signs, and diagnostics; however, these did not include 3D models. How a virtual 3D model and patient-specific health details can impact transition readiness has not been fully explored.

This study aims to expand the scope of these models to include adults with CHD and focus on specific metrics that correlate with transition readiness. We uniquely combined the use of both 3D modeling and ACHD "passports" to deliver one-on-one educational sessions for CHD/ACHD patients. We called these sessions "4D" given they included 3D modeling and health Details (3D + Details = "4D"). We aim to investigate the feasibility of this strategy for improving patient knowledge and transitional readiness.

1.1 Aims

We aim to evaluate whether education with 3D cardiac imaging models improves patients' (adolescents and adults) understanding of their specific heart disease as measured by actual and perceived knowledge; to determine the relationship between actual knowledge and perceived knowledge; and to describe patient satisfaction with the use of digital 3D cardiac models as an educational tool.

2 Methods

2.1 Participant Selection

Participants aged 13 years old or older with a history of CHD who have had previous cardiac magnetic resonance imaging (MRI) were eligible for enrollment. Ethical approval was granted by the Children's National Hospital Institutional Review Board (IRB). All patients were consented at Children's National Hospital, which services all CHD patients in the Washington, DC area with approximately twenty thousand outpatient cardiology visits, five hundred cardiovascular surgical cases, and five hundred cardiac MRI studies on an annual basis. Children's National also has a dedicated ACHD program and services the majority of ACHD patients in the Washington DC area. Study participants were identified and consented by a nurse, either in the pediatric cardiology outpatient clinic or in an outpatient radiology suite prior to the patient's clinically-indicated MRI. In some patients with significant stent artifact on MRI, previous computed tomography data was used to supplement the 3D modeling process. All complexities of CHD were included. Select comorbidities including severe developmental delay and select genetic syndromes with intellectual impairment were considered exclusion criteria. Only English-speaking patients and those with reliable internet connections to attend remote appointments were included.

2.2 Enrollment

As part of an IRB-approved study, participants were recruited through review of electronic health records or during routinely scheduled surveillance MRI studies. After consent, the coordinator scheduled a tele-education session with the patient and/or parent. A total of thirty-four patients consented for the study. Five were consented in cardiology clinic, three of whom completed the educational session. Twenty-nine were consented in the radiology suite, nineteen of whom completed the educational session. There were twelve participants who dropped out from the study (Fig. 1).

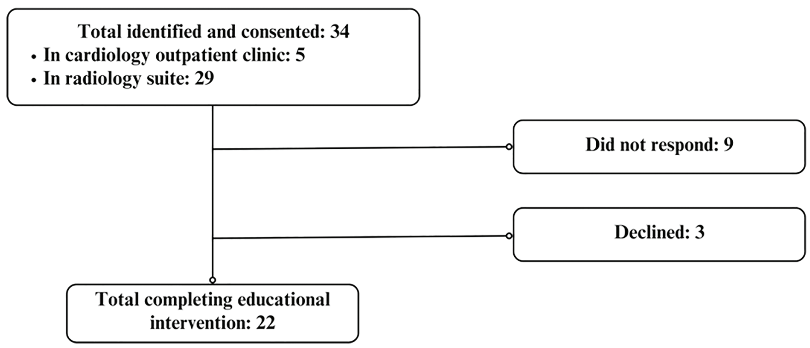

Figure 1: Recruitment flow chart

2.3 3D Model Creation

The 3D datasets were imported into Mimics (Materialise Inc.; Leuven, Belgium) and the relevant intracardiac anatomy was segmented. The segmented imaging dataset was then exported into a stereolithography (STL) file.

The study coordinator and participant together completed the "4D" Passport that included important patient-specific CHD information (e.g., name of CHD, medications, allergies, need for subacute bacterial endocarditis prophylaxis, resting heart rate, most recent electrocardiogram) in addition to the 3D model.

2.4 Pre-Intervention Questionnaire

Participants were first asked to complete a survey assessing actual knowledge; in this study, actual knowledge is defined by the MyHeart questionnaire. This is a validated questionnaire that has been applied by Mackie et al. [8,9] and Stewart et al. [5] to assess patient medical condition knowledge. The MyHeart questionnaire was chosen as it was developed solely for the CHD population, and it also tests the level of specific disease knowledge in domains that our intervention aims to improve. The content of the MyHeart scale is described in Table 1. Question 4 was the only question that was modified; we did not test for the dose of the medication(s).

2.5 Intervention

Educational sessions with participants occurred using teleconferencing via Zoom (Zoom Video Communications; San Jose, CA). An educational curriculum similar to one used in a previous study was applied [13]. The same pediatric cardiologist completed the curriculum with the study subjects, first focusing on normal intracardiac anatomy, then transitioning to the learner's specific anatomy, and key points (Supplement 1). All of this was discussed with language in concordance with participants' level of understanding. Fig. 2 depicts the software that is used to display the model, Cardiac Review 3D

(Indicated Inc.). The customized 3D software allows for transparency of individual models and can also clip through the heart for viewing of anatomic relations in different planes. No clinical recommendations were made during the education session. Questions and active participation were encouraged during this discussion; however, those related to clinical management were deferred to the primary cardiologist. Finally, patients participated in filling in important health details in the "4D" passport via a fact sheet including a digital copy of the 3D model. The "4D" passport summarized the information about the patient's medical information and anatomy (Supplement 1).

Table 1: MyHeart questionnaire

Question #	Question	Question format	Maximum score
1	What is the name of your heart defect/condition? Be as specific as possible.	Short answer	6
2a	Have you had any heart surgeries? □ Yes □ No □ Not sure If yes, how many have you had? If yes, what was the name of the operation(s), or what did the surgeon do?	Multiple choice and short answer	5 (1 if no prior heart surgery)
2b	Have you had any heart catheterizations? □ Yes □ No □ Not sure If yes, how many have you had? If yes, what were they for?	Multiple choice and short answer	5 (1 if no prior heart catheterization)
3	Could you explain your heart defect to someone else? □ Not at all □ A little □ Yes	Multiple choice	2
4	What are the names of the medications you take for your heart?	Short answer	3 (1 if on no heart medication)
5	What are the purposes/reasons for your heart medication?	Short answer	2 (0 if on no heart medication)
6	How long do you think you should be followed by a cardiologist who specializes in congenital heart disease? □ When new problems arise □ For a few more years □ For the rest of my life □ I don't know	Multiple choice	2
7	Do you need to take an antibiotic before you see a dentist? □ Yes □ No □ Don't know If "Yes", why is this antibiotic recommended?	Multiple choice and short answer	2 (1 if correct answer is "no")
8	Did you get any help answering these questions? □ Yes, the internet □ Yes, other source □ Yes, pamphlets/brochures previously given to me about my heart □ No, I answered these questions from memory alone	Multiple choice	Not scored

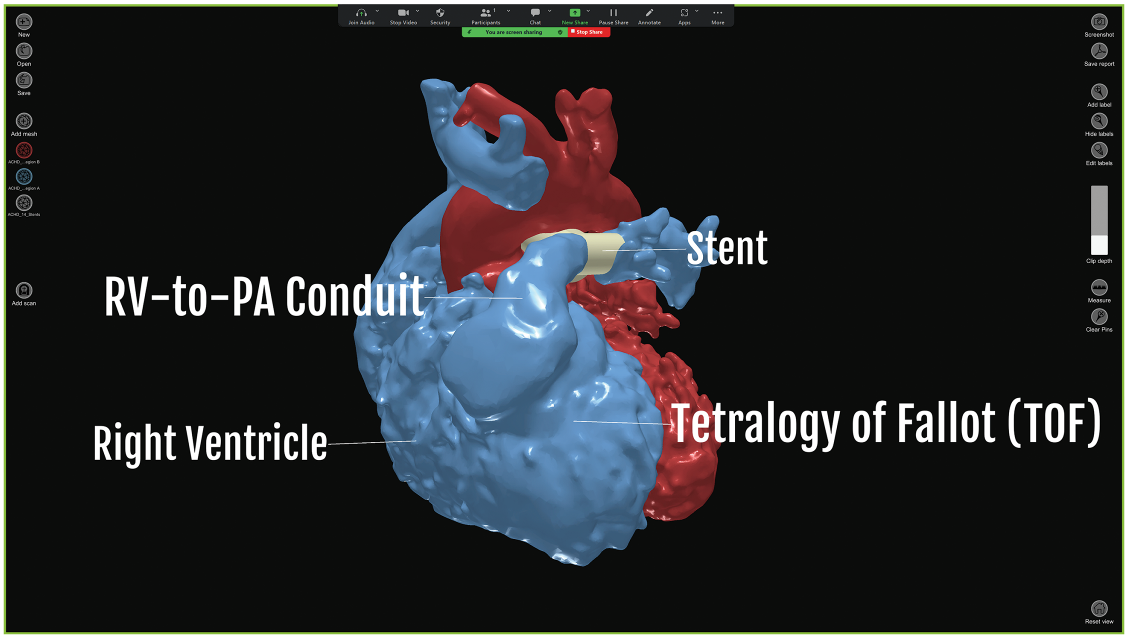

Figure 2: Software used for 3D display of CHD model via Zoom

2.6 Post-Intervention Questionnaires

Immediately following the Zoom conference call, participants completed the same actual knowledge questionnaire. The patients then also completed pre- and post-perceived knowledge questionnaires (Table 2). These were administered together after the intervention to prevent recall bias. The questionnaire was based off Transition Tools developed by pediatric and adult congenital cardiologists [16]. Finally, participants completed a patient satisfaction survey (Table 3). Participants and parents were asked, via Likert scale, to rate the different tools that were used during the consultation. Patients were given the opportunity to provide free text comments.

Table 2: Perceived knowledge questionnaire

Question #	Question	Answer choices
1	I know the name of my heart condition	□ Strongly agree (5) □ Agree (4) □ Neither agree nor disagree (3) □ Disagree (2) □ Strongly disagree (1)
2	I know what surgeries I've had in the past	
3	I know which medications I take for my heart and why	
4	I understand how my heart is different from a normal heart	
5	I understand what my heart looks like	
6	I understand why I need to see a cardiologist as an adult	
7	I understand how to explain my CHD to a doctor I haven't met before (e.g., in the emergency room or the hospital)	

Table 3: Patient satisfaction survey

Question #	Question	Answer choices
1	How satisfied were you with the 3D Model?	□ Very satisfied □ Somewhat satisfied □ Neither satisfied nor dissatisfied □ Somewhat dissatisfied □ Very dissatisfied
2	I found that the education session was:	□ Extremely helpful □ Very helpful □ Somewhat helpful □ Not so helpful □ Not at all helpful
3	The 3D model helped me understand what my heart looks like	□ Strongly agree □ Agree □ Neither agree nor disagree □ Disagree □ Strongly disagree
4	Please leave any comments about your experience	Free text

After the session was finished and patients had completed their questionnaires, patients were provided with a video of their 3D model spinning 360°, a 3D portable document format (PDF) file of their model, and STL files of their 3D model that could be used for printing, if they so desired.

2.7 Actual Knowledge Scoring

Actual knowledge was scored using the same method as Mackie et al. (Supplement 2). These tests were independently scored by two evaluators (MC, YHL) at least six months after the intervention to avoid observer bias.

2.8 Statistical Analysis

Inter-rater reliability was assessed using intraclass correlation coefficient. These are rated as follows: 0.0–0.20 as none to slight, 0.21–0.40 as fair, 0.41–0.60 as moderate, 0.61–0.80 as substantial, and 0.81–1.00 as almost perfect agreement [17,18]. Wilcoxon signed rank test was used to determine whether significant differences existed between pre- and post-intervention actual knowledge scores. Pearson correlation coefficient was used to determine the relationship between perceived knowledge and actual knowledge. Multivariate analyses were also completed to determine potential influences on the primary outcome of actual knowledge improvement. Variables included age, gender, self-reported race, pre-test scores, and complexity of the CHD based on The Society of Thoracic Surgeons-European Association for Cardio-Thoracic Surgery (STAT) category [19] of their surgical history (separating the cohort into STAT category ≥ 3 and <3).

3 Results

3.1 Demographics

Twenty-two participants (50% female) completed the educational session and questionnaires. Their demographics are listed in Table 4. The average age was 24 with an inter quartile range of 15–28 years and a range of 13–42 years. The most common congenital heart disease types were Transposition of the Great Arteries and Tetralogy of Fallot.

Table 4: Study patient demographics

Variable	Number (%); mean ± SD
Sex	
Male	11 (50%)
Female	11 (50%)
Age	23.8 ± 9.42
Self-reported race	
Caucasian	13 (59.1%)
Black	5 (22.7%)
Other/Unknown	4 (18.2%)
Congenital heart disease and cardiac surgeries	
Transposition of the great arteries	7 (31.8%)
Arterial switch operation	5 (22.7%)
Rastelli procedure with RV-PA conduit	1 (4.5%)
Mustard repair	1 (4.5%)
Tetralogy of Fallot	6 (27.3%)
Transannular patch repair	3 (13.6%)
RV-PA conduit	3 (13.6%)
Single ventricle	3 (13.6%)
Fontan palliation	2 (9.1%)
RVOT patch	1 (4.5%)
Aortic anomalies	3 (13.6%)
Balloon valvuloplasty of aortic valve	1 (4.5%)
Ross	1 (4.5%)
Stent of coarctation	1 (4.5%)
Truncus arteriosus	2 (9.1%)
Truncus repair with RV-PA conduit	2 (9.1%)
Partial anomalous pulmonary vein return	1 (4.5%)
ASD patch repair	1 (4.5%)
Surgical interventions	
Number 1	9 (40.9%)
Number >1	13 (59.1%)

3.2 Actual Knowledge, Perceived Knowledge, Satisfaction, and Qualitative Comments

Intraclass correlation coefficient was 0.89 ($p < 0.0001$). Actual knowledge increased from 75% ± 15% to 89% ± 20% ($p = 0.00043$). Perceived knowledge increased in five of seven questions. Actual knowledge correlated with perceived knowledge ($r = 0.608$, $p < 0.0001$). Ninety-one percent of patients ranked the 3D model as "very satisfactory;" ninety-five percent ranked the educational session as "very helpful" or "extremely helpful." Questionnaire results are summarized in Table 5.

Table 5: Questionnaire results

a. Actual knowledge

	Pre-intervention	Post-intervention	*p*-value
Total score	75% ± 15%	89% ± 20%	**0.00043**

b. Perceived knowledge

Question #	Question	Pre-intervention Likert score	Post-intervention Likert score	*p*-value
1	I know the name of my heart condition	4.55 ± 0.74	4.86 ± 0.35	0.25
2	I know what surgeries I've had in the past	3.86 ± 1.17	4.82 ± 0.39	**0.00148**
3	I know which medications I take for my heart and why	4.62 ± 2.30	4.92 ± 2.49	0.75
4	I understand how my heart is different from a normal heart	4.00 ± 0.87	4.82 ± 0.39	**0.00148**
5	I understand what my heart looks like	2.95 ± 1.56	4.73 ± 0.46	**0.00064**
6	I understand why I need to see a cardiologist as an adult	4.23 ± 1.02	4.82 ± 0.39	**0.0140**
7	I understand how to explain my CHD to a doctor I haven't met before (e.g., in the emergency room or the hospital)	3.59 ± 1.22	4.64 ± 0.49	**0.00096**

c. Satisfaction questionnaire

1. How satisfied were you with the 3D model?	
Very satisfied	20 (91%)
Somewhat satisfied	2 (9%)
Neither satisfied nor dissatisfied	0
Somewhat dissatisfied	0
2. I found the educational session was:	
Extremely helpful	18 (81.8%)
Very helpful	3 (13.6%)
Somewhat helpful	1 (4.5%)
Not so helpful	0
Not at all helpful	0
3. The 3D model helped me understand what my heart looks like:	
Strongly agree	21 (95.5%)
Agree	1 (4.5%)
Neither agree nor disagree	0
Disagree	0
Strongly disagree	0

On multivariate analysis, we found that improvement in actual knowledge scores was associated with lower baseline score and STAT category ≥3, but independent of age, gender or race (Table 6). Likewise, baseline actual knowledge scores were not associated with age, gender, race, or STAT category (Supplementary Table S1). Study participants' qualitative comments regarding the educational session are presented in Table 7.

Table 6: Multivariate linear regression of actual knowledge improvement

Variable	Parameter estimate	Standard error	T value	*p*-value
Intercept	8.514	1.699	5.011	**<0.0001**
Age	0.3414	0.04342	0.7862	0.4440
Sex (female)	0.5129	0.8264	0.6933	0.4987
Pre-test score	−0.4176	0.08413	4.963	**0.0002**
STAT category ≥3	3.073	0.9680	3.175	**0.0063**
Self-reported race (Black)	−0.7565	1.078	0.7018	0.4935
Self-reported race (other)	0.8568	1.079	0.7942	0.4394

Table 7: Qualitative comments

This makes me feel so much better seeing it like this. Seeing it visually helped me to understand it more. Would like to see it after the catheterization. Would like to do it again.
It is very interesting how the heart works, got me thinking about searching more about my heart condition.
Although I had a lot of knowledge about my medical history… this session explained it in a way that brought everything together, filled in a lot of blanks, and made it so I can explain my condition more easily.
I learned a lot of specific answers to questions I have had throughout the years. Seeing the 3D model was SO helpful, since 2D models can only do so much. That was the first time I realized how my pulmonary valves were physically related to my aorta in space. I am so excited to make a 3D print of my very own heart!
I learned a lot about my heart condition and what it looks like and what it all means. I highly recommend similar sessions for everyone who has gone through this.
The 3D model was extremely helpful. Session was informative and educational. I got to learn a lot about my heart.

4 Discussion

This study prospectively implemented a tele-education session using 3D models as a tool to improve each adolescent or adult patient's knowledge of his/her specific CHD. This study also utilized the "4D"-passport including the 3D model and a summary of all the patient's pertinent CHD information. This educational strategy was found to increase both actual and perceived knowledge for prospective ACHD patients.

Transition readiness for ACHD is a multi-faceted assessment, of which a patient's actual and perceived knowledge should be a critical element. Perceived knowledge in particular can be readily and quickly ascertained in the clinical setting. Uzark et al. developed a unique questionnaire assessing the following domains: knowledge deficits, self-efficacy, and self-management behaviors [6]. They found perceived knowledge to be an accurate reflection of actual knowledge, which was consistent with our study. The MyHeart Questionnaire developed by Mackie et al. tested actual knowledge [8] in addition to self-efficacy and self-advocacy. The aspect of actual patient medical knowledge is not always investigated in transitional readiness [9,20–25]. Additionally, actual patient knowledge in some studies has been tested, but not tied to outcomes related to transition readiness [7,16,26–28]. However, in general, knowledge deficits were found to be significantly negatively correlated with self-efficacy and self-management [8,29]. Thus, strategies to improve patient knowledge such as our "4D" passport should continue to be developed.

The "4D" educational session allowed for both visual representation with the 3D model and integration of pertinent health details simultaneously. Patients with a complex Mustard baffle can visualize the potential regions of narrowing and understand why further follow-up and subsequent interventions are required. The need for prophylactic antibiotics could be understood by visualizing the implanted transcatheter valve in the heart. The reasons for long-term follow-up for repaired Tetralogy of Fallot could be conveyed by visualizing the dilation of the right heart from chronic pulmonic insufficiency. Our multivariate analysis suggests that the use of the "4D" passport could potentially be targeted to those with CHD complexity or those with less baseline understanding of their own CHD condition.

While these virtual models were not tangible, participants still found the 3D models to be useful when presented in a teleconference setting. Furthermore, the use of teleconferencing and digital models and 3D PDF files allowed this study to be conducted during the COVID-19 pandemic, while still allowing patients an opportunity to interact with their personalized model and avoiding the need to individually print each 3D model which has resource implications [30,31].

To date, there have been few studies utilizing virtual, patient-specific 3D models for patient-specific education in CHD. Biglino et al. determined that a majority of parents rated the 3D models as "very useful" and allowed for more immediate understanding compared to 2D images [10]. Other studies have used the creation of a passport, online tools, or virtual apps, but did not incorporate a 3D model [8,9,14]. For medical trainees, such models allow for better spatial understanding of complex cardiac conditions and have been generally met with increased learner satisfaction [11,12]. In our study [13], we successfully used digital 3D models and demonstrated improvement in measured actual knowledge under the same schema as Biglino et al. [10]. Thus, this educational strategy should serve as a useful component for CHD patients to be educated about transition readiness in the long term.

This study has several limitations, including the limited sample size and the lack of a control group which may affect the generalizability of the results. We acknowledge that this is a relatively small pilot study compared to the number of patients cared for at our institution, but we hope to incorporate some of the elements from the study into clinical practice as 3D models have been used for patient education on an *ad hoc* basis. Only English-speaking patients were included. The perceived knowledge questionnaire used questions from established questionnaires [16]; however, some of the questions were modified (to tailor towards assessment of the 3D intervention) and were not validated. Also, only immediate post-intervention knowledge was tested without any long-term follow-up or outcomes data, although this was not attempted due to concerns of the COVID-19 pandemic remaining a significant confounder. Finally, the study also focused mainly on the domain of knowledge and did not assess other domains of transition readiness (e.g., self-efficacy, self-management, self-advocacy). Future studies should focus on these aspects, in addition to determining usefulness for patient knowledge and satisfaction for providers in the outpatient and/or emergency setting. In addition to a larger sample size, studies will also stratify effectiveness by the complexity of CHD.

5 Conclusion

In conclusion, the "4D" tele-education intervention increased patient actual and perceived knowledge. Also, patients were satisfied with the intervention and with their personalized 3D model. This increase in knowledge may help to improve transition readiness and successful transition to adult care. More research must be completed to study the long-term effectiveness of this intervention.

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Availability of Data and Materials: Readers can access the data used in the study by contacting the corresponding author.

Ethics Approval: Research involving human subjects complied with all relevant national regulations, institutional policies and is in accordance with the tenets of the Helsinki Declaration (as revised in 2013) and has been approved by the authors' Institutional Review Board (Children's National Hospital). All the patients consented for the study.

Conflicts of Interest: The authors declare that they have no conflicts of interest to report regarding the present study.

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