Combining patient-specific, digital 3D models with tele-education for adolescents with CHD

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Original Article

Abstract

Introduction: Adolescents with CHD require transition to specialised adult-centred care. Previous studies have shown that adolescents' knowledge of their medical condition is correlated with transition readiness. Three-dimensional printed models of CHD have been used to educate medical trainees and patients, although no studies have focused on adolescents with CHD. This study investigates the feasibility of combining patient-specific, digital 3D heart models with tele-education interventions to improve the medical knowledge of adolescents with CHD. *Methods:* Adolescent patients with CHD, aged between 13 and 18 years old, were enrolled and scheduled for a tele-education session. Patient-specific digital 3D heart models were created using images from clinically indicated cardiac magnetic resonance studies. The tele-education session was performed using commercially available, web-conferencing software (Zoom, Zoom Video Communications Inc.) and a customised software (Cardiac Review 3D, Indicated Inc.) incorporating an interactive display of the digital 3D heart model. Medical knowledge was assessed using pre- and post-session questionnaires that were scored by independent reviewers. *Results:* Twenty-two adolescents completed the study. The average age of patients was 16 years old (standard deviation 1.5 years) and 56% of patients identified as female. Patients had a variety of cardiac defects, including tetralogy of Fallot, transposition of great arteries, and coarctation of aorta. Post-intervention, adolescents' medical knowledge of their cardiac defects and cardiac surgeries improved compared to pre-intervention (p < 0.01). *Conclusions:* Combining patient-specific, digital 3D heart models with tele-education sessions can improve adolescents' medical knowledge and may assist with transition to adult-centred care.

CHD in the paediatric population is individually unique, with similar heart lesions having varied clinical significance depending on anatomical morphology. Even after surgical repair, CHD is a lifelong condition requiring long-term monitoring for complications and eventual transition of care to a provider specialised in adult care.[1–3] Unfortunately, approximately half of adolescents do not successfully transfer to adult CHD care resulting in suboptimal outcomes.[4]

Patients frequently cite a lack of knowledge about their heart disease and the need for long-term follow-up by an adult congenital cardiologist as the reason for gaps in care.[5,6] Previous research has also correlated readiness for transition and psychosocial quality of life with increased medical knowledge.[7,8] Medical knowledge of CHD, however, is difficult to impress upon young patients. Cardiologists often use hand drawn pictures to help explain CHD. However, CHD is inherently a 3D condition, and these methods rely on an individual's ability to use 2D images to imagine and reconstruct a mental model of a complex 3D heart.[9,10]

Research with paediatric trainees has demonstrated the ability for 3D to improve spatial understanding of complex, patient-specific cardiac conditions.[11,12] Using 3D models to educate patients and families remains a relatively new concept, but early studies show promising results. Biglino et al used patient-specific 3D-printed heart models to teach patients and family members, showing improvement in medical comprehension and high user satisfaction. This study used 3D-prints which can have high cost and long processing times.[13,14]

Tele-education has been utilised for children with chronic diseases, including CHD. However, in previous studies, review of patient-specific CHD anatomy was done in-person.[15–17] More recently, advances in web-based technologies allow for anatomical teaching to occur remotely.[18] Remote visits can improve access to education and are more reliably attended.[19–21] Furthermore, in light of the novel coronavirus-19 pandemic, patients are being encouraged to utilise telemedicine visits to avoid possible exposure to the coronavirus-19 virus.[22,23] Utilising digital 3D heart models during remote visits may help maintain patient engagement and help patients to better visualise their anatomy.
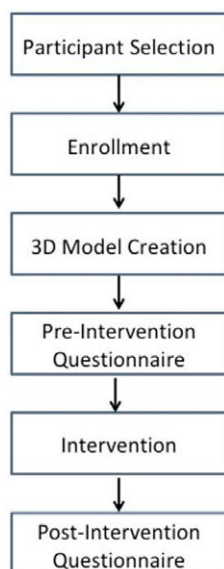
Figure 1. Study design.

Figure 2. 3D examples of CHD included in study, in comparison to a structurally normal heart (far left).

The aim of our study is to examine the feasibility of combining digital patient-specific 3D heart models with tele-education to improve medical knowledge for adolescents with CHD.

Methods

This was a prospective pre-post study that was performed at a tertiary paediatric care centre with approval from the Institutional Review Board. Written informed consent/assent was obtained for each patient. The overall work flow of the study is depicted in Figure 1.

Patient selection

Patients, aged 13–18 years old, with a history of CHD and previous cardiac MRI imaging were eligible. Patients with select comorbidities including moderate/severe developmental delay and specific genetic syndromes were excluded. Due to resource limitations, language services could not be hired and thus adolescents who did not speak English were also excluded.

Enrollment

Eligible patients were recruited either through direct referral from paediatric cardiologists or through self-referral. After consenting to the study, patients were scheduled for a 30-minute tele-education session with a designated paediatric cardiologist.

3D model creation

3D datasets obtained from prior MRI imaging were imported into Mimics (Materialise; Leuven, Belgium), a commercially available 3D segmentation software. The relevant cardiac anatomy was segmented and processed into digital 3D heart models per lab standards.[11] The models were exported as two separate stereolithography files representing the separate pulmonary (systemic veins, right atrium, right ventricle, pulmonary arteries) and systemic circulation (pulmonary veins, left atrium, left ventricle, aorta). Figure 2 demonstrates representative CHD anatomy in this study.
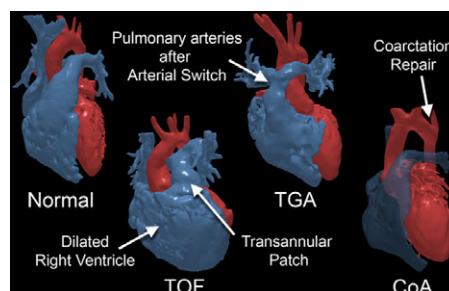
Pre-intervention questionnaire

The medical knowledge and baseline characteristics of the adolescents were assessed. This was done via a two-part questionnaire, having adolescents describe, in free-text format, their cardiac defect ("What is the name of your heart disease?") and their cardiac surgery ("What is the name of your heart surgery?"). Additionally, baseline quality of life of the patients was assessed using a clinically validated Paediatric Cardiac Quality of Life Index questionnaire.[24,25]

Intervention

Educational sessions with patients and designated paediatric cardiologist occurred at prearranged times using web-conferencing software (Zoom, Zoom Communications Inc). Parental participation was optional. To maintain consistency of the tele-education session, the same paediatric cardiologist (YHL) led all sessions in the study. Display of the digital 3D heart model was performed using the interactive software Cardiac Review 3D (Indicated Inc.), which has been previously used for medical trainees and nurses.[26] The patient was able to see the cardiologist and view the digital 3D heart model simultaneously. Figure 3 depicts the combination of software used for the session.

A standardised educational curriculum was created and followed for each session (Supplementary Materials, Table E1). The curriculum contains dedicated time for learning normal cardiac anatomy and patient-specific cardiac anatomy including previous heart surgeries. Time was also reserved for discussing transitioning to adult-centred care and patient wellness. No specific clinical recommendations were made during the education sessions. Questions regarding anatomy and surgery were encouraged, but any patient-specific questions related to clinical management were referred to the patient's primary cardiologist.

Following the session, patients were mailed a USB drive that contained a video of their 3D heart model and the digital stereolithography files that could be used to print a 3D model of their heart.

Post-intervention questionnaire and qualitative feedback

Immediately following the web-conferencing session, patients completed the same two-part questionnaire regarding their cardiac defect and cardiac surgery. A free-text response option was included to allow patients and family members to provide qualitative feedback.

Medical knowledge scoring

Answers to patients' questionnaires were scored into "classes" of medical knowledge by two attending paediatric cardiologists (AC, LO) who were blinded to whether the questionnaires were

Figure 3. Conventional web-conferencing software was combined with cardiac display software via share screen function to display 3D heart model during education session.

Medical Knowledge Scoring System	
Class I	Good or very good knowledge (correct name of diagnosis, use of medical language)
Class II	Adequate knowledge (description sufficient to decipher the diagnosis, at least in part, using lay language, eg, 'narrowing' instead of 'stenosis' or 'hole in the heart' instead of 'atrial/ ventricular septal defect');
Class III	Vague knowledge (some indication of the diagnosis by identifying a correct keyword, eg, 'pulmonary valve' for 'tetralogy of Fallot', however, not sufficient to describe the condition in full);
Class IV	Poor knowledge (blank response, incorrect keywords)

Figure 4. Schema used to score level of medical knowledge.

completed before or after the educational intervention. Scoring was completed using the same schema developed by Biglino et al.[13] Scoring rubric displayed in Figure 4.

Statistical analysis

A weighted Cohen's kappa statistic was used to determine inter-rater reliability for the medical knowledge scoring. Inter-rater reliability was interpreted as follows: 0.01–0.20 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.[27,28] A Wilcoxon signed rank test was calculated to determine the statistical difference in medical knowledge before and after the educational intervention. p-Values < 0.05 were considered statistically significant.[29]

Results

Demographics

A total of 22 adolescent patients were enrolled in the study and completed the pre-intervention questionnaire, educational session, and post-intervention questionnaire. The average age of patients was 16.0 years old with a standard deviation of 1.5 years. Forty-six percent of patients identified as male and 54% identified as female. Table 1 shows additional demographic characteristics of patients.

Patients had a variety of different cardiac defects and surgeries. The most common defects included tetralogy of Fallot, transposition of the great arteries, and aortic coarctation. Additional defects listed as "other" in Table 1 included hypoplastic left heart syndrome, tricuspid atresia, Ebstein anomaly, pulmonary stenosis, ventricular septal defect, and atrial septal defect. Additional surgeries listed as "other" in Table 1 included Fontan palliation, pulmonary balloon valvuloplasty, valve replacement, patch repair of ventricular septal defect, and trans-catheter device closure of atrial septal defect.

Three patients in the study reported comorbidities, including nephrolithiasis, short stature, lymphedema, scoliosis, and mild developmental delay. There were two patients with Noonan syndrome and one patient with DiGeorge syndrome.

Most patients used a computer for the tele-education session. In addition to the 30-minute allotted time, approximately 5 minutes was required to set up the session (such as re-emailing the web-conferencing link or troubleshooting the connection). The sessions were often scheduled on a weekend or late afternoon to accommodate the adolescent's school and activity schedule.

Medical knowledge

Table 2 displays the medical knowledge scoring results for the patients pre and post the tele-education intervention. The median post-test ranks were statistically significantly higher than the median pre-test ranks for both cardiac defects (median post versus median pre respectively, p < 0.01) and cardiac surgeries (median post versus median pre respectively, p < 0.01). Prior to the intervention, 47.7% of patients were scored having a class I understanding of their heart defect and 18.5% had class I understanding of their surgical history. Post-intervention, this increased to 88.6 and 68.2%, respectively.

Inter-rater reliability

There was substantial overall agreement between the two evaluators for cardiac defect knowledge classification, with a linearly

Table 1. Characteristics of patients

Variable	No. of patients (%)
Sex	
Male	10 (45.5)
Female	12 (54.5)
Age	
13–15 years	6 (27.2)
15–18 years	16 (72.8)
Race	
Caucasian	15 (68.2)
Black	5 (22.7)
Other	2 (9.1)
Cardiac defect	
Tetralogy of Fallot	6 (27.3)
Transposition of the great arteries	5 (22.7)
Aortic coarctation	4 (18.2)
Other	7 (31.8)
Cardiac surgeries	
Transannular patch repair	6 (27.3)
Arterial switch	4 (18.2)
Coarctation repair with end-to-end anastomoses	3 (13.6)
Other	9 (40.9)
Paediatric Cardiac Quality of Life Index	Average survey score (range)
Total	78.02 (60.7–100.0)
Disease impact	38.84 (29.4–50.0)
Psychosocial	39.18 (31.3–50.0)

Table 2. Medical knowledge

Prior to intervention	Prior to intervention (%)	Post-intervention (%)
Cardiac defect		
Class I	47.7	88.6
Class II	15.9	11.4
Class III	4.5	0
Class IV	31.8	0
Cardiac surgeries		
Class I	18.2	68.2
Class II	6.8	22.7
Class III	22.7	4.5
Class IV	52.3	4.5

weighted kappa score of 0.75 [0.60–0.90]. There was also substantial overall agreement between the two evaluators for cardiac surgeries knowledge classification with a linearly weighted kappa score of 0.74 [0.62–0.86].

Table 3. Qualitative comments

Patients
I liked the fact that I could visualise my daughter's heart and better understand where she stands with her heart disease
It helped both me and my child better understand his heart. Also the doctor explained information in a way we could understand
I liked how the goal was to educate the person on their heart condition
It helped me better understand the "why" of things
I liked how they explained what I didn't know clearly so I could understand
I learned things about my heart that I didn't know
Leaders
Most patients used computers for session. Some patients used smart phone
Setting up the session required ~5 minutes for most sessions
Tele-health allowed for flexible appointment times and this allowed patients to avoid missing school

Qualitative comments

Comments were collected from patients following the intervention and are reported in Table 3. In general, patients and family members appreciated the ability to visualise the CHD of the patient.

Discussion

This study focused on using patient-specific digital 3D heart models as a means to improve medical knowledge and therefore enhance engagement in care in adolescents with CHD. The study group included patients with a diverse range of cardiac defects and surgeries. After a 30-minute web-conferencing session using 3D models, medical knowledge scores demonstrated statistically significant improvement. This result demonstrates the feasibility of combining novel tele-education and 3D modelling to teach adolescents about CHD.

While previous studies have shown that printed 3D heart models are helpful for teaching patients and families, this study demonstrates that digital models are also effective.[13] While digital 3D models cannot allow patients to touch a heart model, our results show that the tactile benefit of a 3D printed model may not be necessary for patients. One chief benefit that likely remains with the use of digital 3D models is that they can improve learner satisfaction.[11] Compared with printed models, digital models can be easily shared virtually and are significantly more cost-effective.[14]

To our knowledge, this is the first study that combines two technologies of tele-conferencing and 3D modelling. Most patients receive education about their heart conditions during face-to-face encounters with their physician.[30] However, time is limited during clinic visits to provide this teaching. Separating these encounters maximises the benefit of both modalities. Qualitative comments from this study highlight the value of the virtual teaching sessions and relative ease which families were able to set up and participate.

There is previous literature to support that improved medical knowledge and self-efficacy improves psychosocial quality of life.[31] We intended to assess the effect of this intervention on psychosocial quality by assessing Paediatric Cardiac Quality of Life Index results 6 months following the intervention; however, this portion

of the study was suspended by the emergence of the coronavirus-19 pandemic, which would have likely confounded the results.[32]

There were several limitations involved in this study. First, this study focused on feasibility and thus has a small number of patients without a control group. This study also demonstrated immediate improvement in medical knowledge but did not test patients for long-term knowledge retention. Due to financial constraints, we were unable to provide interpreter services for non-English speaking patients and thus excluded an important group of potential patients. In addition, our sessions required patients to have computer or phone with internet access, likely excluding patients without this resource.

Future studies will include a larger number of patients and a control group to compare tele-education sessions with and without 3D digital heart models. In addition, the patient questionnaire should be expanded to test patient's understanding of their disease management and the lifestyle implications of their CHD. Additional studies should also explore the potential for tele-education interventions with patient-specific 3D heart models to improve psychosocial quality of life.

In summary, the novel approach of combining patient-specific, digital 3D models with tele-education is a feasible method of teaching for adolescents with CHD. This method has the potential to improve medical knowledge and may subsequently increase readiness and likelihood of successful transition into adult-centred care.

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