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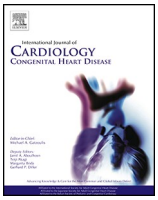

Infective endocarditis: Awareness, knowledge gaps and behaviours amongst adults with congenital heart disease

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ABSTRACT

Background: Adults with congenital heart disease (ACHD) have an increased risk of infective endocarditis (IE), associated with significant morbidity and mortality. This risk is compounded by patient-related factors, including lack of awareness of IE and the presence of a learning disability (LD). Our study sought to evaluate patients' understanding of the risks and symptoms of IE and to identify patients who could benefit from targeted education.

Methods: Patients attending the outpatient department of a tertiary ACHD referral centre completed a questionnaire that assessed their knowledge, attitudes and behaviours towards IE. Baseline demographics and clinical data were collected from electronic patient records.

Results: A total of 132 ACHD patients completed the questionnaires (age 41.7 ± 16.4 years, 50 % male, 11 % with an LD). Only 37.1 % of patients accurately defined IE, none of whom had an LD. Most patients chose pyrexia (47 %) and tiredness (39.4 %) as potential symptoms of IE, however, none correctly identified all symptoms. Only 19.7 % were aware of the requirement for prolonged antibiotic treatment for IE. A third of all patients reported that they would have made lifestyle changes had they been aware of the complications of IE. There was a statistically significant association between learning disability and poor level of awareness in the questionnaire.

Conclusions: Our study demonstrates awareness issues regarding IE among ACHD patients, highlighting the need to invest further on patient education. This should start at the time of transition from paediatric to adult services and continue lifelong, with emphasis on patients with a learning disability.

1. Introduction

The population of adults with congenital heart disease (ACHD) is growing rapidly, with over 90 % of babies born with congenital heart disease (CHD) surviving to adulthood [1]. This is owed to improved neonatal screening and advancements in the surgical and medical management of these patients in childhood [2]. ACHD patients are at a significantly increased risk of developing infective endocarditis (IE) [3]. Studies have reported the incidence of IE in this population to be as high as 1.1 per 1000 patient-years, as opposed to 5–7 cases per 100,000 patient-years in the general population [4,5]. IE is typically associated with prolonged hospitalisations, significant morbidity and in-hospital mortality as high as 6 % [6].

The increased IE risk in CHD is attributable to structural heart changes (native or postoperative) that facilitate pathogen colonisation due to turbulent and high-velocity non-laminar blood flow, which exposes the sub-endocardial collagen, recurrent exposure to cardiac interventions and the presence of intracardiac foreign objects such as prosthetic valves [7,8]. Lifestyle measures must be taken to reduce IE risk in CHD and include optimal dental and skin hygiene, avoidance of tattoos, body piercing and intravenous drug use. Antibiotic prophylaxis for dental or certain interventional procedures is currently reserved to a minority of individuals.

As with many diseases, preventive measures play a key role in reducing the risk of developing IE and its complications, but patient-related factors, such as education and awareness of IE, can influence the uptake of these measures. Specifically, younger CHD patients who are transitioning from paediatric to adult care may find accepting responsibility for their health challenging [9]. During this transitional phase to independence, CHD patients are susceptible to poor decision-making that can stem from lack of awareness and the high risk-taking behaviours often observed amongst this age group [10]. It is,

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thus, important to ensure patients are equipped with the knowledge required to reduce their risk profile and be vigilant to symptoms of IE from as early as adolescence. The establishment of 'transition clinics' for CHD patients has been an important step in addressing such a challenge [11,12].

Our study sought to evaluate the understanding of the risks, preventative measures, and symptoms of IE among ACHD patients followed in a tertiary centre. Moreover, we sought to identify ACHD patients with particularly limited knowledge of IE and engagement in high-risk behaviours who would most benefit from more intensive and targeted education.

2. Methods

2.1. Study population and data collection

Consecutive patients who attended the outpatient department of our tertiary ACHD centre were provided with a questionnaire (Fig. 1) developed through modification of the pre-existing Leuven Knowledge Questionnaire for Congenital Heart Disease. This included questions on patients' knowledge of IE: awareness of risk factors, potential complications of IE and safe practices, and when to seek medical attention [13]. The threshold to correctly identify IE was the use of a combination of 'heart' and 'infection', or synonymous descriptors. For the reference of correct questionnaire answers, please see Fig. 2. Patients were asked to independently select as many answers as they felt appropriate. All questionnaires were collected after the consultation and analysed. Baseline demographic and clinical characteristics were collected from clinical notes and electronic patient records. This was a cross-sectional study of ACHD patients as part of a quality improvement project for which ethical approval was not required.

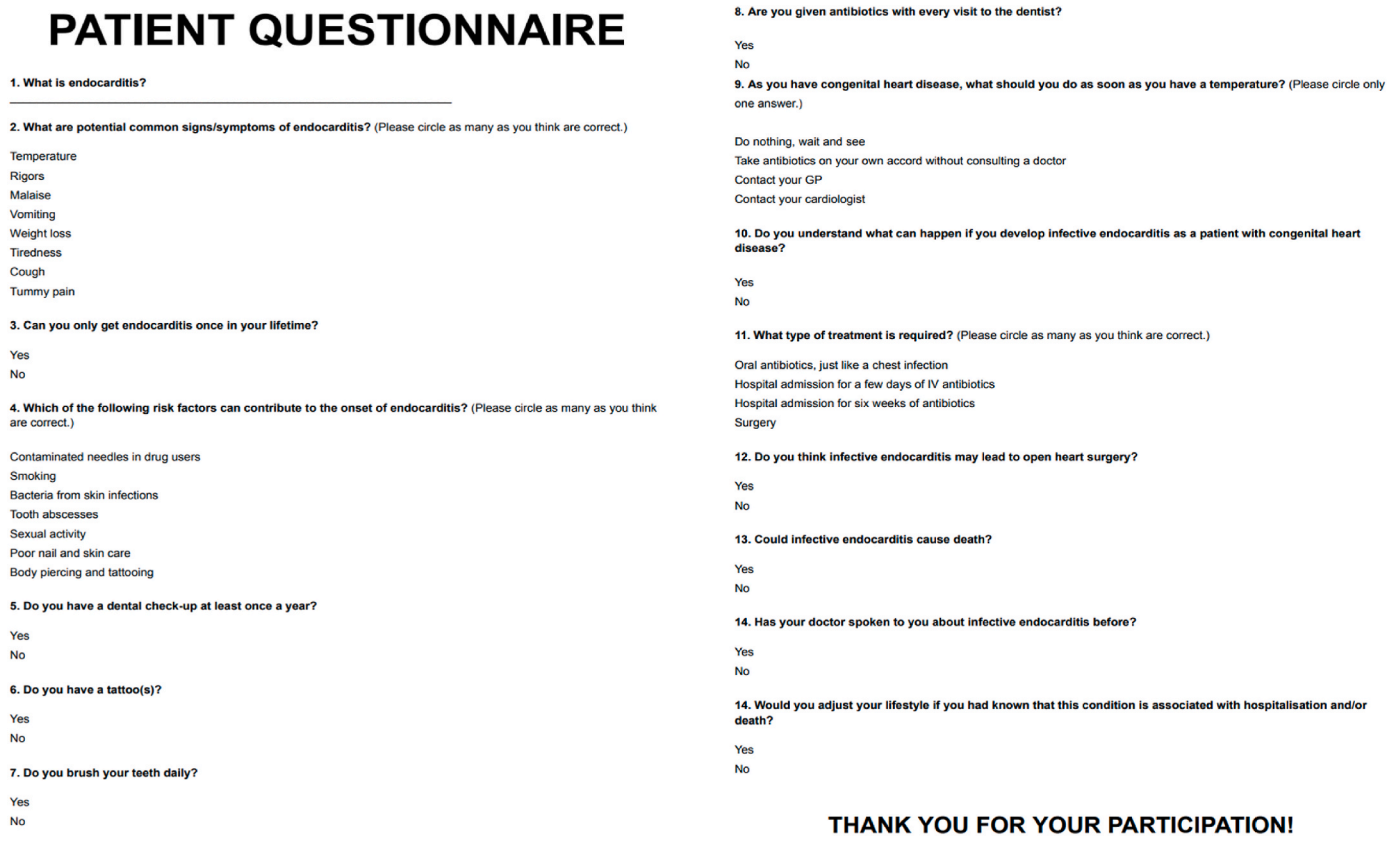
2.2. Statistical analysis

All analyses were performed using the statistical software package, R (version 4.01) [14]. Baseline demographics and clinical data (independent variables) were collected from electronic patient records. These included age, gender, diagnosis, history of IE, total previous surgical or percutaneous interventions, presence of a learning disability and whether the patient was already able to define endocarditis. Chi square analysis was used to test for significance between baseline characteristics. We chose to use patients' ability to define endocarditis as a predictor for their questionnaire score in order to evaluate whether patients' knowledge of the existence of endocarditis was related to their engagement in preventive measures and understanding of its consequences and treatment.

The questionnaire was divided into four sections.

- Awareness of IE symptoms (pyrexia, rigors, malaise, vomiting, weight loss, tiredness, cough and abdominal pain)
- Knowledge of IE risk factors (shared needle use, smoking, skin infections, tooth abscesses, unprotected sexual activity, nail and skin care, piercings and tattoos)
- Engagement in preventive measures (annual dental checks, brushing teeth at least twice a day, avoiding tattoos, knowledge of when to take antibiotics, and correct knowledge of response to a fever)
- Knowledge of the treatment and potential consequences of IE (whether IE can be contracted more than once, knowledge of antibiotic treatment, likely length of hospital stay, potential need for surgery, risk of death)

The highest total possible questionnaire score was 30, with incorrect or missing answers scoring a '0', and correct answers scoring a '1'. We assigned cut-off pass marks for the total questionnaire score and for each section score. A detailed outline of the questionnaire sections, the



PATIENT QUESTIONNAIRE

1. What is endocarditis?

_____

2. What are potential common signs/symptoms of endocarditis? (Please circle as many as you think are correct.)

Temperature
Rigors
Malaise
Vomiting
Weight loss
Tiredness
Cough
Tummy pain

3. Can you only get endocarditis once in your lifetime?

Yes
No

4. Which of the following risk factors can contribute to the onset of endocarditis? (Please circle as many as you think are correct.)

Contaminated needles in drug users
Smoking
Bacteria from skin infections
Tooth abscesses
Sexual activity
Poor nail and skin care
Body piercing and tattooing

5. Do you have a dental check-up at least once a year?

Yes
No

6. Do you have a tattoo(s)?

Yes
No

7. Do you brush your teeth daily?

Yes
No

8. Are you given antibiotics with every visit to the dentist?

Yes
No

9. As you have congenital heart disease, what should you do as soon as you have a temperature? (Please circle only one answer.)

Do nothing, wait and see
Take antibiotics on your own accord without consulting a doctor
Contact your GP
Contact your cardiologist

10. Do you understand what can happen if you develop infective endocarditis as a patient with congenital heart disease?

Yes
No

11. What type of treatment is required? (Please circle as many as you think are correct.)

Oral antibiotics, just like a chest infection
Hospital admission for a few days of IV antibiotics
Hospital admission for six weeks of antibiotics
Surgery

12. Do you think infective endocarditis may lead to open heart surgery?

Yes
No

13. Could infective endocarditis cause death?

Yes
No

14. Has your doctor spoken to you about infective endocarditis before?

Yes
No

14. Would you adjust your lifestyle if you had known that this condition is associated with hospitalisation and/or death?

Yes
No

THANK YOU FOR YOUR PARTICIPATION!

Fig. 1. Questionnaire.

EXPLANATION OF QUESTIONNAIRE

1. What is endocarditis
Total score = 1
Patients only scored if they used a combination of heart and infection (or any synonymous word).

2. What are the potential common signs/symptoms of endocarditis?
Total score = 8, since all answers are correct options.

3. Can you only get endocarditis once in your lifetime?
Total score = 1
Correct answer is 'no'.

4. Which of the following risk factors can contribute to the onset of endocarditis?
Total score = 7, since all answers are correct options.

5. Do you have a dental check-up at least once a year?
Total score = 1
Correct answer is 'yes'.

6. Do you have a tattoo(s)?
Total score = 1
Correct answer is 'no'.

7. Do you brush your teeth daily?
Total score = 1
Correct answer is 'yes'.

8. Are you given antibiotics with every visit to the dentist?
Total score = 1
Correct answer is 'yes'.

9. As you have congenital heart disease, what should you do as soon as you have a temperature?
Total score = 1
Correct answer is 'Contact your GP' or 'Contact your cardiologist'.

10. Do you understand what can happen if you develop infective endocarditis as a patient with congenital heart disease?
Total score = 1
Correct answer is 'yes'.

11. What type of treatment is required? (Please circle as many as you think are correct.)
Total score = 2
Correct answer is 'hospital admission for six weeks of antibiotics' and 'surgery'.

12. Do you think infective endocarditis may lead to open heart surgery?
Total score = 1
Correct answer is 'yes'.

13. Could infective endocarditis cause death?
Total score = 1
Correct answer is 'yes'.

Fig. 2. Explanation of questionnaire.

associate scoring criteria and cut-off pass mark values are provided in Table 1.

Subsequent group analysis was performed using logistic regression to quantify the relationship between each predictor and the likelihood of passing the total questionnaire and its individual sections. This analytical approach enabled the model to provide the odds that a particular predictor could forecast whether the patient succeeded or failed. Finally, a forward stepwise selection was performed on each of the logistic regression models to define models with the best Akaike Information Criterion.

3. Results

3.1. Baseline demographics

A total of 132 questionnaires were collected from 132 patients (see baseline characteristics in Table 2). Mean age was 41.7 ± 16.4 years and 66 (50.0 %) were male. Patients had a wide range of congenital defects: 8 (6.1 %) had simple, 96 (72.7 %) had moderate and 28 (21.2 %) had great complex CHD as per the American Heart Association ACHD Anatomic and Physiological (AP) classification system [15]. The most common diagnoses were atrio-ventricular septal defect (29.5 %), tetralogy of Fallot (12.1 %) and right ventricular outflow tract obstruction (11.4 %). Only 7 (5.3 %) patients had a previous history of IE. The vast majority (n = 107, 81.1 %) had undergone at least one previous surgical or percutaneous intervention. There were 15 (11.4 %) patients who had a learning disability,

Results from the questionnaires are displayed in Table 3 and results of the multivariate regression analyses are displayed in Tables 4–8.

3.2. Awareness of symptoms

In total, 49 (37.1 %) patients were able to correctly define IE. When asked to select symptoms of endocarditis, pyrexia (n = 62, 47.0 %) and tiredness (n = 52, 39.4 %) were the two most selected symptoms, while rigors (n = 9, 6.8 %) was the least commonly selected symptom. Only 30 (22.7 %) patients were able to select a minimum of three IE symptoms.

Multivariate logistic regression revealed that patients with a history of IE, and those who were able to define IE were significantly more likely to score higher in the symptoms section (OR 21.8; CI 2.95–464.01, 0 = 0.009 and OR 2.71; CI 1.00–7.56, p = 0.052, respectively) (see Table 4).

3.3. Knowledge of risk factors for IE

Over half of all patients selected tooth abscess (n = 76, 57.6 %), body piercing and tattoos (n = 66, 50 %), and contaminated needles in drug users (n = 57, 43.2 %) as risk factors. Fewer patients selected bacteria from skin infections (n = 52, 39.4 %), poor nail and skin hygiene (n = 34, 25.8 %), smoking (n = 31, 25.3 %) and unprotected sexual activity (n = 15, 11.4 %) as risk factors for IE. Less than half of all patients (n = 62, 47.0 %) were able to correctly identify more than two risk factors for IE.

Multivariate logistic regression demonstrated that patients who were able to define IE were more likely to score higher in this section (OR 4.34; CI 1.83–10.78, p = 0.001). However, those with the presence of a learning disability and those with medium or great complexity ACHD were more likely to score poorly in this section (OR 0.19; CI 0.03–0.92, p = 0.064 and OR 0.36; CI 0.11–1.06, p = 0.074, respectively) (see Table 5)0.12345.

Table 1
Questionnaire scoring system.

Sub-section: Awareness of symptoms of IE	Correct answer	Score
Symptoms x 8	Yes (for all)	1 x 8 = 8
Total section score	**8**	
Cut-off score for section	**<3 vs ≥ 3**	
Sub-section: Knowledge of risk factors of IE	**Correct answer**	**Score**
Risk factors x 7	Yes (for all)	1 x 7 = 7
Total section score	**7**	
Cut-off score for section	**<3 vs ≥ 3**	
Sub-section: Engagement in preventive measures of IE and knowledge of when to seek help	**Correct answer**	**Score**
Do you get an annual dental check-up?	Yes	1
How many times do you brush your teeth each day?	≥2 times/ day	1
Do you have a tattoo?	No	1
Do you know whether you have to take antibiotics at the dentist?	Yes	1
If you have a temperature, would you: do nothing?	No	1
If you have a temperature, would you: self-administer antibiotics?	No	1
If you have a temperature, would you: call the doctor (e.g. GP or cardiologist)?	Yes	1
Total section score	**7**	
Cut-off score for section	**<6 vs ≥ 6**	
Sub-section: Knowledge of treatment and potential consequences of IE	**Correct answer**	**Score**
Can you get IE once only?	No	1
Do you know how IE is treated?	Yes	1
Is the treatment of IE: oral antibiotics?	No	1
Is the treatment of IE: for a few days?	No	1
Is the treatment of IE: for a few weeks?	Yes	1
Could the treatment of IE involve surgery?	Yes	1
Could the treatment of IE involve open heart surgery?	Yes	1
Could IE be fatal?	Yes	1
Total section score	**8**	
Cut-off score for section	**<5 vs ≥ 5**	
TOTAL QUESTIONNAIRE SCORE	**30**	
CUT-OFF SCORE FOR QUESTIONNAIRE	**<15 vs ≥ 15**	

Abbreviations: IE, infective endocarditis; GP, general practitioner.

3.4. Engagement in preventive measures

The majority of patients had at least one annual dental check-up (n = 109, 82.6 %). Most patients (n = 121, 91.7 %) selected 'yes' to brushing their teeth daily whilst 11 patients (8.3 %) answered 'no' or did not answer the question. The majority of patients (n = 89, 67.4 %) answered 'no' to being given antibiotics with every visit to the dentist and 11 patients (8.3 %) did not answer. A total of 24 patients (18.5 %) had tattoos. Only 55 of 132 (41.7 %) patients were able to achieve the pass-mark for this section.

Multivariate logistic regression revealed that patients who had undergone a higher number of surgical or percutaneous interventions were more likely to score higher in this section (OR 1.38; CI 1.06–1.83, p = 0.018) whereas those with the presence of a learning disability were more likely to score poorly in this section (OR 0.16; CI 0.02–0.73, p = 0.035) (see Table 6).

3.5. Knowledge of the consequences of IE

The majority of patients (n = 88) were not aware that IE could recur in their lifetime, while only 5 patients (5.6 %) were aware that IE could occur more than once in their lifetime. The remainder (n = 43, 32.6 %) did not answer. Patients were then given a choice of what they would do if they developed a temperature, with 28 patients (21.2 %) choosing that they would 'do nothing, wait and see'. Only 8 patients (6.1 %) stated that they would contact their cardiologist, whilst 88 patients (67.2 %) stated that they would contact their GP. No patient selected the option for self-administering antibiotics.

Table 2
Baseline characteristics of patients.

Characteristic	Patients who passed[a] N = 52	Patients who failed[a] N = 80	Total N = 132	P-value
Age (years); mean (SD)	43.1 (17.0)	40.8 (16.1)	41.7 (16.4)	–
Male	28	38	66 (50.0 %)	0.475
Simple complexity CHD	3	5	8 (6.1 %)	0.913
Medium or great complexity CHD	49	75	124 (93.9 %)	
History of IE	7	0	7 (5.3 %)	**0.001**
Total number of surgical or percutaneous intervention ≥1	46	61	107 (81.1)	0.802
Presence of learning disability	1	14	15 (11.4 %)	**0.006**
Recalled explanation of IE by healthcare provider	20	13	33 (25.0 %)	**0.004**
Able to define IE	29	20	49 (37.1 %)	**<0.001**

Abbreviations: CHD, complex heart disease; IE, infective endocarditis.
[a] Defined as patients who passed or failed the total questionnaire, for which the cut-off pass mark was 15 out of 30 marks.

The majority of patients (n = 88, 66.7 %) were not aware of the consequences of developing IE whilst having underlying CHD, and 14 patients (10.6 %) did not answer. Although patients were told they could select more than one answer to the treatment of IE, patients either selected one or none. Just over a quarter of patients (n = 36, 27.3 %) were able to identify the correct treatment of IE (hospital admission for six weeks of IV antibiotics and/or surgery), with most (n = 57, 43.2 %) not answering and the remainder selecting the wrong answers (n = 39, 29.6 %). Only one half of the patients (n = 65, 49.2 %) were aware that IE could require open heart surgery, with 18 patients (13.6 %) selecting an answer of 'no' and 49 patients (37.1 %) not answering the question. Over half of the patients (n = 80, 60.6 %) were aware that IE could be fatal, with the remainder either not answering the question (n = 43, 32.6 %) or selecting 'not' (n = 9, 6.8 %). Only 26 patients (19.7 %) were able to correctly select that IE requires a few weeks' treatment. Only a third of patients (n = 44) were able to pass this section.

Multivariate logistic regression revealed that patients with a history of IE and those who were able to define endocarditis were more likely to score higher in this section (OR 8.15; CI 1.16–165.34, p = 0.008 and OR 3.30; CI 1.38–8.11, p = 0.008, respectively) (see Table 7).

3.6. Total questionnaire score

Patients scored a median of 10 (5, 14.25) points in the questionnaire out of a total available score of 27. Only 33 patients (25 %) selected that their doctor had spoken to them about IE before, whilst 72 patients (54.5 %) stated that their doctor had not spoken to them about IE, and 27 patients (20.1 %) did not answer. When asked if they would change their practice had they known about the risk of IE, 43 patients (32.6 %) said yes, 43 patients (32.6 %) said no, whilst 46 patients (34.8 %) did not select an answer. Overall, there were 52 out of 132 (39.4 %) patients who were able to correctly answer at least half of the questions and pass the questionnaire.

Multivariate logistic regression revealed that patients who were able

Table 3
QUESTIONNAIRE results.

	N = 132 (%)	N = 117 (%)	N = 15 (%)	
Questionnaire response	Total[a]	No LD[b]	LD[c]	P = value
1. What is endocarditis?				
Correct	49 (37.1)	49 (41.9)	0 (0)	<0.01
Incorrect/unanswered	83 (62.9)	68 (58.1)	15 (100)	
2. What are the potential common symptoms of endocarditis? (Please circle as many as you think are correct.)				
Temperature	62 (47.0)	59 (50.4)	3 (20.0)	0.03
Rigors	9 (6.8)	9 (7.7)	0 (0)	0.27
Malaise	16 (12.1)	16 (13.7)	0 (0)	0.13
Vomiting	21 (15.9)	14 (12.0)	7 (46.7)	<0.01
Weight loss	19 (14.4)	19 (16.2)	0 (0)	0.09
Tiredness	52 (39.4)	51 (43.6)	1 (6.7)	<0.01
Cough	21 (15.9)	16 (13.7)	5 (33.3)	0.05
Tummy pain	13 (9.8)	9 (7.7)	4 (26.7)	0.02
3. Can you only get endocarditis once in your lifetime?				
Yes/unanswered	48 (36.4)	33 (28.2)	15 (100)	<0.01
No	84 (63.6)	84 (71.8)	0 (0)	
4. Which of the following risk factors can contribute to the onset of endocarditis? (Please circle as many as you think are correct.)				
Contaminated needles in drug users	57 (43.2)	55 (47.0)	2 (13.3)	0.01
Smoking	28 (21.2)	22 (18.8)	6 (40.0)	0.06
Bacteria from skin infections	52 (39.4)	50 (42.7)	2 (13.3)	0.03
Tooth abscesses	76 (57.6)	74 (63.2)	2 (13.3)	<0.01
Sexual activity	15 (11.4)	13 (11.1)	2 (13.3)	0.80
Poor nail and skin care	34 (25.8)	32 (27.4)	2 (13.3)	0.24
Body piercing and tattooing	66 (50.0)	62 (53.0)	4 (26.7)	0.05
5. Do you have a dental check-up at least once a year?				
Yes	109 (82.6)	100 (85.5)	9 (60.0)	0.01
No/unanswered	23 (17.4)	17 (14.5)	6 (40.0)	
6. Do you have a tattoo(s)?				
Yes	24 (18.2)	24 (18.2)	0 (0)	0.05
No/unanswered	108 (81.8)	93 (81.8)	15 (100)	
7. Do you brush your teeth daily?				
Yes	121 (91.7)	113 (96.6)	8 (53.3)	<0.01
No/Unanswered	11 (8.3)	4 (3.4)	7 (46.7)	
8. Are you given antibiotics with every visit to the dentist?				
Yes	32 (24.2)	30 (25.6)	2 (13.3)	0.29
No/Unanswered	100 (75.8)	87 (74.4)	13 (86.7)	
9. As you have congenital heart disease, what should you do as soon as you have a temperature? (Please circle only one answer.)				
Do nothing, wait and see	28 (21.2)	20 (17.1)	8 (53.1)	<0.01
Take antibiotics on your own accord without consulting a doctor	0 (0)	0 (0)	0 (0)	1.00
Contact your GP	88 (66.7)	86 (73.5)	2 (13.3)	<0.01
Contact your cardiologist	8 (6.1)	8 (6.8)	0 (0)	0.30
Unanswered	8 (6.0)	3 (2.6)	5 (33.3)	<0.01
10. Do you understand what can happen if you develop infective endocarditis as a patient with congenital heart disease?				
Yes	30 (22.7)	28 (23.9)	2 (13.3)	0.36
No/Unanswered	102 (77.3)	89 (76.1)	13 (86.7)	
11. What type of treatment may be required? (Please circle as many as you think are correct.)				
Oral antibiotics, just like a chest infection	10 (7.6)	9 (7.7)	1 (6.7)	0.89
Hospital admission for a few days of IV antibiotics	29 (22.0)	29 (24.8)	0 (0)	0.03
Hospital admission for six weeks of antibiotics	26 (19.7)	26 (22.2)	0 (0)	0.04
Surgery	10 (7.6)	9 (7.7)	1 (6.7)	0.89
Unanswered	57 (43.2)	43 (36.8)	14 (93.3)	<0.01
12. Do you think infective endocarditis may lead to open heart surgery?				
Yes	65 (49.2)	63 (54.1)	2 (13.3)	<0.01
No/Unanswered	67 (50.8)	54 (45.9)	13 (86.7)	
13. Could infective endocarditis cause death?				
Yes	80 (60.6)	75 (64.1)	5 (33.3)	0.02
No/Unanswered	52 (39.4)	42 (35.9)	10 (66.7)	
14. Has your doctor spoken to you about infective endocarditis before?				
Yes	33 (25.0)	33 (28.2)	0 (0)	0.02
No/Unanswered	99 (75.0)	84 (71.8)	15 (100)	
14. Would you adjust your lifestyle if you would have known that this condition is associated with hospitalisation and/or death?				
Yes	43 (32.6)	41 (35.1)	2 (13.3)	0.09
No/Unanswered	89 (67.4)	76 (64.9)	13 (86.7))	

[a] Results provided as % of total patients.
[b] Results provided as % of total number of patients without an LD.
[c] Results provided as % of total number of patients with a learning disability (LD).

Table 4
Multivariate logistic regression: Awareness of IE symptoms (pyrexia, rigors, malaise, vomiting, weight loss, tiredness, cough and abdominal pain).

	Multivariate Logistic (N = 132)		
	Odds ratio	95 % CI	p-value
Age	0.99	0.95 to 1.01	0.341
Male gender	0.50	0.19 to 1.26	0.148
Medium or great complexity ACHD	1.51	0.47 to 5.59	0.507
Simple complexity ACHD	1.89	0.21 to 13.7	0.538
History of IE	**21.8**	**2.95 to 464.01**	**0.009**[a]
Total number of surgical/percutaneous interventions	0.90	0.63 to 1.23	0.538
Presence of learning disability	1.03	0.14 to 5.17	0.970
Doctor explained IE	1.36	0.43 to 4.09	0.587
Able to define endocarditis	**2.71**	**1.00 to 7.56**	**0.052**[a]

ACHD: adult congenital heart disease; IE: infective endocarditis; CI: confidence interval.
[a] significant if P < 0.1.

to define endocarditis were more likely to score well in this section (OR 2.11; CI 0.91–4.97, p = 0.083) whereas those with the presence of a learning disability were more likely to score poorly in this section (OR 0.16; CI 0.01–0.94, p = 0.092) (see Table 8).

Table 5
Multivariate logistic regression: Knowledge of IE risk factors (shared needle use, smoking, skin infections, tooth abscesses, unprotected sexual activity, nail and skin care, piercings and tattoos).

	Multivariate Logistic (N = 132)		
	Odds ratio	95 % CI	p-value
Age	1.01	0.98 to 1.03	0.509
Male gender	1.44	0.66 to 3.21	0.363
Medium or great complexity ACHD	**0.36**	**0.11 to 1.06**	**0.074**[a]
Simple complexity ACHD	0.27	0.04 to 1.66	0.168
History of IE	0.87	0.15 to 6.86	0.884
Total number of surgical/percutaneous interventions	1.05	0.79 to 1.40	0.747
Presence of learning disability	**0.19**	**0.03 to 0.92**	**0.064**[a]
Doctor explained IE	1.67	0.59 to 4.73	0.330
Able to define endocarditis	**4.34**	**1.83 to 10.78**	**0.001**[a]

ACHD: adult congenital heart disease; IE: infective endocarditis; CI: confidence interval.
[a] significant if P < 0.1.

Table 6
Multivariate logistic regression: Engagement in preventive measures (annual dental checks, brushing teeth at least twice a day, avoiding tattoos, knowledge of when to take antibiotics, and correct knowledge of response to a fever).

	Odds ratio	95 % CI	p-value
Age	0.99	0.97 to 1.02	0.547
Male gender	1.38	0.66 to 2.93	0.394
Medium complexity ACHD	1.60	0.59 to 4.62	0.368
Simple complexity ACHD	1.89	0.33 to 11.04	0.467
History of IE	2.53	0.46 to 19.76	0.309
Total number of surgical/percutaneous interventions	**1.38**	**1.06 to 1.83**	**0.018**[a]
Presence of learning disability	**0.16**	**0.02 to 0.73**	**0.035**[a]
Doctor explained IE	0.90	0.34 to 2.34	0.828
Able to define endocarditis	0.80	0.34 to 1.84	0.603

ACHD: adult congenital heart disease; IE: infective endocarditis; CI: confidence interval.
[a] significant if P < 0.1.

3.7. Forward stepwise selection

Forward stepwise selection identified the best combinations of predictors to model the questionnaire score through optimisation of the logistic regression results.

- Awareness of symptoms: Ability to define IE and history of IE
- Knowledge of risk factors for IE: Ability to define IE, presence of a learning disability and the presence of medium or great complexity ACHD
- Engagement in preventive measures: Presence of a learning disability and the number of surgical or percutaneous interventions
- Knowledge of the consequences of IE: Ability to define IE, history of IE and the presence of a learning disability
- Total score: Ability to define IE, history of IE and the presence of a learning disability

Table 7
Multivariate logistic regression: Knowledge of the treatment and potential consequences of IE (whether IE can be contracted more than once, knowledge of antibiotic treatment, likely length of hospital stay, potential need for surgery, risk of death).

	Odds ratio	95 % CI	p-value
Age	0.99	0.96 to 1.02	0.443
Male gender	1.37	0.60 to 3.15	0.452
Medium complexity ACHD	0.78	0.27 to 2.31	0.644
Simple complexity ACHD	1.82	0.29 to 11.49	0.513
History of IE	**8.15**	**1.16 to 165.34**	**0.068**[a]
Total number of surgical/percutaneous interventions	0.81	0.58 to 1.09	0.184
Presence of learning disability	0.24	0.01 to 1.51	0.203
Doctor explained IE	1.65	0.59 to 4.56	0.336
Able to define endocarditis	**3.30**	**1.38 to 8.11**	**0.008**[a]

ACHD: adult congenital heart disease; IE: infective endocarditis; CI: confidence interval.
[a] significant if P < 0.1.

Table 8
Multivariate logistic regression: Total questionnaire score.

	Odds ratio	95 % CI	p-value
Age	1.01	0.98 to 1.03	0.485
Male gender	1.17	0.53 to 2.59	0.696
Medium complexity ACHD	0.68	0.24 to 1.92	0.460
Simple complexity ACHD	0.75	0.12 to 4.24	0.746
History of IE	3.77	1.28 to 5.42	0.991
Total number of surgical/percutaneous interventions	0.96	0.71 to 1.27	0.763
Presence of learning disability	**0.16**	**0.01 to 0.94**	**0.092**
Doctor explained IE	1.72	0.63 to 4.71	0.286
Able to define endocarditis	**2.11**	**0.91 to 4.97**	**0.083**

ACHD: adult congenital heart disease; IE: infective endocarditis; CI: confidence interval.
* significant if P < 0.1.

4. Discussion

Our study highlights important knowledge gaps related to IE and behavioural factors in patients attending a tertiary ACHD centre, a finding which was more pronounced amongst patients with a learning disability. Less than half of the cohort was able to select the risk factors for IE and its clinical presentation. Reassuringly, the majority of patients (80 %) had regular dental reviews, yet only around half maintained optimal daily dental hygiene and 18 % had tattoos. A large number were also unaware that IE is potentially fatal and may lead to cardiac surgery.

Our results suggest that a patient's history is an important factor in their overall knowledge and attitudes towards IE. Specifically, a positive history of IE and a higher number of previous surgical or percutaneous procedures appear to contribute to this knowledge, presumably due to their first-hand experience with the disease and the surgical prophylaxis measures they have undergone, respectively. This implies that patients without such experiences will likely have poor knowledge of this important disease and reduced engagement in preventive measures. Those with medium or great complexity CHD exhibited lower awareness of the risk factors for IE, which corroborates prior studies documenting elevated IE risk in these populations [16]. Interestingly, while the

concept of a physician explaining IE did not significantly predict better questionnaire performance, the ability to define IE was a predictor for achieving higher questionnaire scores. This suggests that merely being informed about the existence or risk of IE may be inadequate, and that a more comprehensive understanding of IE is necessary for patients to fully grasp its importance and prevention.

Our results are somewhat consistent with prior studies from around the world which describe a significant paucity in awareness related to IE. Only 6 % and 16 % of patients could correctly identify IE in studies from Germany and Canada, respectively [17,18]. Our study contributes further to the literature; while awareness levels were much higher with over a third of patients being able to define IE, it is of great concern that even in a tertiary centre, patients' knowledge of one of the most devastating, yet largely preventable complications of CHD remains sub-optimal. Targeted education for ACHD patients is crucial to address this knowledge gap.

Education received during routine appointments should be supplemented by additional methodologies. In fact, due to the need for extensive subspecialty training of a multidisciplinary team, funding remains a major obstacle in expanding ACHD services [19]. Digital advancements, such as virtual teleconference clinics established during the COVID-19 pandemic, could help improve educational efficiency while reducing costs and logistical barriers [20]. One study identified strong interest from adolescents in a mobile application focusing on ACHD information, blog forums, mentorship forms and checklists – this may even be appropriate given the changes in lifestyle measures during this digital era adjustment [21]. As highlighted by Ricci et al. different models of education that leverage psychological insights from behavioural economic theory may involve the use of 'nudges' to help patients make healthy decisions without feeling restricted [22]. Such tailored strategies may help healthcare professionals improve health-related behaviour among patients in the vulnerable period of adolescence [23,24]. Moreover, mobile phone applications that leverage artificial intelligence can enhance ACHD patients' education on infective endocarditis by providing personalised, real-time and age-appropriate content based on individual health data, helping patients understand their specific risk factors. AI-powered tools such as chatbots or virtual assistants may also deliver accurate, accessible educational resources, improving patient engagement and adherence to preventive measures [25].

A structured transition service can significantly contribute to knowledge, especially in younger patients. This involves equipping patients with the necessary knowledge and support to optimise how they navigate their condition throughout their lifetime. Appointments at transition clinics include the patient, their family, and a member of the transition team, typically a transition clinical nurse specialist (CNS). In selected patients, their paediatrician and ACHD specialist may be present, especially around the time of transfer to adult services, with occasional requirement for a psychologist or other [15]. The transition CNS plays a central role in establishing communication with young CHD patients, providing education and addressing unhealthy behaviours, such as smoking. This should occur in an environment that allows adequate time for patients to discuss their concerns and emotions, and facilitate healthy lifestyle decisions. Indeed, ACHD physicians alone may not be able to allocate sufficient time to transition due to constraints within the healthcare system [26].

Our study also underscores concerns about IE awareness and engagement in preventive measures among ACHD patients with learning disabilities, as evidenced by lower questionnaire scores in this subgroup. Given that approximately 10 % of the ACHD population have a learning disability, practitioners may need to customise their approach towards educating this vulnerable patient group [27]. For example, the National Health Service England's 'Congenital Heart Disease Standards & Specifications' advise that age- and cognitive development-appropriate information should be provided to patients, with all ACHD healthcare professionals engaging in continual professional development in relation to working with adults with a learning disability [28]. It also advises that the ACHD Specialist Nurses make appropriate referrals to appropriate agencies or specialists and work closely with the learning disability team, as well as with family members and carers. Moreover, support should be provided for patients with other types of disability, e.g. interpreters/advocates for patients with deafness.

An area of controversy and debate over the last decade has been the role of IE prophylaxis for patients with CHD [29,30]. Over the last 2 decades, the indications for prophylaxis have changed significantly, limiting its use to a minority of patients, which has resulted in some confusion amongst patients and even healthcare providers [31]. Well-designed education can overcome this issue and optimise patient care by allowing them to adjust to evolving guidelines.

Our study highlights deficits in IE awareness and risk prevention among our ACHD cohort, which should lead to improvements in patient education. Beyond optimising ACHD and transition services, it would be valuable to involve other health practitioners in this effort, such as general practitioners who are at the 1st line of care. Future work should also assess ACHD patients' knowledge on other aspects of their condition, such as planning pregnancies and exercise limitations.

4.1. Limitations

Our study has certain limitations. Firstly, Firstly, our sample size is relatively small (132 participants), a factor which stems from the nature of a questionnaire-based, single-centre study. This limitation is reflected in the wider confidence intervals observed, as exemplified by the logistic regression analysis on patients' knowledge of IE symptoms. Similarly, the limited sample size, in combination with the extensive set of predictors included in the forward stepwise regression, increases the likelihood of overfitting the statistical model. This is notable when considering that only seven patients had a history IE and only 14 had a learning disability, which were two significant predictors in our models. This raises the possibility that the observed relationships may result from chance occurrences rather than reflecting genuine underlying associations.

Secondly, the presence of a learning disability was ascertained through electronic patient records, which indicated a 'learning disability' or 'developmental delay'. However, the precise degree of the learning disability was not formally evaluated. Additionally, while all clinic patients were deemed to have the capacity to provide informed consent from the questionnaire, we acknowledge that participants completed questionnaires without our observation, so we could not confirm if they consulted others albeit to learn about IE themselves. Despite this potential limitation, our findings highlight that the majority of patients were still unable to answer the questions correctly. Thirdly, the significant heterogeneity within this CHD population limited our ability to conduct additional analyses and multivariate models. Nevertheless, the issue of IE is common to all CHD patients and therefore, knowledge dissemination should be similar for most patients.

Fourthly, we recognize that our question in relation to patients requiring antibiotics at the dentist should have accounted for each patient's underlying diagnosis, which would influence whether they require antibiotics or not. However, we were still able to demonstrate that at least 11 patients did not know the answer, since they did not answer the question. In fact, most (10 out of 28 patients) patients with great complexity CHD did not answer the question, highlighting a need to reinforce preventive habits among these patients.

Fifth, since the data for this study were retrieved from questionnaires, our study is more likely to be subjected to biases, for example, selection bias and non-response bias. Nonetheless, questionnaire studies are the primary way to collect data on certain topics, and they provide important insights that are otherwise difficult to obtain through other research methods.

Lastly, we recognize that our questionnaire could have included more open-ended questions to allow patients more freedom in expressing their thoughts. Qualitative analysis through patient interviews could

provide further insight into not only the knowledge that patients have acquired in relation to IE but could also inform best practice for educating individuals and different patient subgroups such as those with a learning disability. However, simplified questionnaires are less intimidating for participants and can be easier to answer.

5. Conclusions

Education of patients and their families on important topics such as IE is a fundamental part of CHD management, starting from the time of CHD diagnosis and continuing throughout their lifetime. Education is best provided through collaboration between physicians and clinical nurse specialists, with the latter playing a crucial role in the transition period. Where appropriate, information pertaining to IE must be provided in a manner suited to CHD patients with a learning disability or other disability. Additionally, as more non-specialists, including general practitioners, are likely to encounter ACHD patients, we must support our colleagues by sharing information surrounding the preventive measures and early identification of IE in this patient group. Multimodal targeted awareness platforms, including interactive mobile phone applications and online forums may prove advantageous.

CRediT authorship contribution statement

S. Haider: Writing – original draft, Methodology, Formal analysis, Data curation, Conceptualization. **K. Krishanthasan:** Writing – original draft, Methodology, Formal analysis, Data curation, Conceptualization. **I. Olakorede:** Methodology, Formal analysis, Data curation. **A. Constantine:** Writing – review & editing, Supervision. **I. Rafiq:** Writing – review & editing, Supervision, Conceptualization. **K. Dimopoulos:** Writing – review & editing, Supervision, Conceptualization.

Generative AI

No generative AI or AI-assisted technologies were used for this research paper.

Ethics

This was a cross-sectional study of ACHD patients as part of a quality improvement project for which ethical approval was not required. The privacy rights of human subjects have been observed and informed consent was obtained for participation in the questionnaire either from the patient or patient's next of kin.

The baseline log odds is 0.2069, corresponding to a percentage score of 55.2 %. For a subject with the presence of a learning disability, this will decrease significantly, $p = 0.0288$, to 44.6 %.

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Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper; one of the authors (KD) serves as an IJCCHD Editorial Board Member but was not involved with the handling of this paper.

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