Health risk behaviors in adolescents and emerging adults with congenital heart disease: psychometric properties of the Health Behavior Scale-Congenital Heart Disease

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Abstract

Background: To optimize long-term outcomes, patients with congenital heart disease (CHD) should adopt health-promoting behaviors. Studies on health behavior in afflicted patients are scarce and comparability of study results is limited. To enlarge the body of evidence, we have developed the Health Behavior Scale-Congenital Heart Disease (HBS-CHD).

Aims: We examined the psychometric properties of the HBS-CHD by providing evidence for (a) the content validity; (b) validity based on the relationships with other variables; (c) reliability in terms of stability; and (d) responsiveness.

Methods: Ten experts rated the relevance of the HBS-CHD items. The item content validity index (I-CVI) and the averaged scale content validity index (S-CVI/Ave); the modified multi-rater Kappa and proportion of missing values for each question were calculated. Relationships with other variables were evaluated using six hypotheses that were tested in 429 adolescents with CHD. Stability of the instrument was assessed using Heise's method; and responsiveness was tested by calculating the Guyatt's Responsiveness Index (GRI).

Results: Overall, 86.3% of the items had a good to excellent content validity; the S-CVI/Ave (0.81) and multi-rater Kappa (0.78) were adequate. The average proportion of missing values was low (1.2%). Because five out of six hypotheses were confirmed, evidence for the validity of the HBS-CHD based on relationships with other variables was provided. The stability of the instrument could not be confirmed based on our data. The GRI showed good to excellent capacity of the HBS-CHD to detect clinical changes in the health behavior over time.

Conclusion: We found that the HBS-CHD is a valid and responsive questionnaire to assess health behaviors in patients with CHD.

Keywords

Heart defects, congenital, health behavior, life style, adolescence, validity, reliability, psychometric properties

Introduction

As adolescents born with congenital heart disease (CHD) transition to adulthood, they are supposed to increasingly take responsibility over their health. During this developmental transition, adolescents become more independent and search for their own identity, develop a social network of peers, and increasingly adhere to their own values, beliefs, and customs.[1]

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This developmental stage is generally characterized by experimenting behaviors such as smoking tobacco, use of illicit drugs, and alcohol.[2,3]

Although to date about 90% of children born with CHD reach adulthood,[4] they remain susceptible to development of arrhythmias, ventricular dysfunction, endocarditis, and premature mortality.[5,6] In order to prevent these complications and to optimize long-term outcomes, patients should conduct health-promoting behaviors. These behaviors comprise moderate use of alcohol, avoidance of smoking cigarettes, no use of illicit drugs, excellent oral hygiene, adequate engagement in physical activities, and good dietary habits.[7]

Current literature shows that studies investigating health behaviors in adolescents and emerging adults with CHD are scarce. Studies demonstrated that rates of substance use among these youngsters were lower compared to general population samples or healthy peers.[1,6,8,9] Nonetheless, 28% of adolescents and 54% of young adults with CHD performed significant substance use during the past 30 days.[9] Excellent oral hygiene, characterized by annual dental visits, flossing, and daily brushing of teeth, was identified in a small proportion of patients.[9,10] The comparability of these study results, however, is limited because no standardized method to collect data on health behavior exists to date.[9] Although to date some self-administered questionnaires are available for assessing health behaviors in patients with CHD,[1,9–12] to the best of our knowledge none of them cover all items relevant for afflicted patients comprehensively. Furthermore, previously developed surveys differ substantially in wording, components of health behavior measured, and time frames used to assess health risk behavior.[1,9–12]

In order to enlarge the body of evidence and to support clinical practice in assessing health risk behaviors of patients with CHD, we developed the Health Behavior Scale-CHD (HBS-CHD). This scale is a comprehensive tool for measuring and detecting potentially health-compromising behaviors in patients with CHD. Hence, the HBS-CHD contains items that are particularly relevant for afflicted patients because these components may worsen patients' outcomes.

However, to use this tool in research or clinical practice, psychometric properties should be determined. The aim of this study was therefore to assess the psychometric properties of the HBS-CHD.

Methods

Development of the HBS-CHD

The HBS-CHD (see Appendix 1) was partially based on existing instruments comprising questions regarding health behavior in adolescents or adults.[9,13–21] Twenty-five questions on 22 components of health risk behavior in individuals with CHD were formulated. Four questions regarding consumption of alcohol were based on the Alcohol Use Disorders Identification Test (AUDIT).[13,19,20] Three questions on the use of tobacco during the past month were based on the Youth Risk Behavior Survey (YRBS).[15,16,18] Seven questions, developed for a population-based study in the Netherlands, asked respondents about the use of (illicit) drugs, sleeping pills, sedatives, and tranquillizers during the past month.[21] Information on dental hygiene was obtained through four questions derived from the Self-reported Health Risk Behaviors questionnaire.[9,22] Seven questions pertained to physical activity levels, which were inspired by the Baecke questionnaire for the Measurement of a Person's Habitual Physical Activity.[14,17] Levels of physical activity were operationalized using the classification schemes published by Godin et al.[23] and Durnin et al.[24] These questions were put in a specific lay-out to guide respondents through the HBS-CHD instrument.

Psychometric properties

To evaluate the psychometric properties of the HBS-CHD, we used the approach described and terminology used in the Standards for Educational and Psychological Testing.[25] More specifically, we evaluated evidence for content validity; validity evidence based on relationships with other variables; reliability evidence based on stability; and responsiveness evidence. These evaluations were undertaken concomitantly.

Content validity of the HBS-CHD. To evaluate the content validity, ten experts (three nurses, seven cardiologists) in pediatric cardiology and Adult Congenital Heart Disease were invited to rate the relevance of all 22 HBS-CHD items, using a four-point rating scale (1=not relevant; 4=very relevant).[26] Free text space was provided to give additional comments. Calculation of both the item content validity index (I-CVI) and the averaged scale content validity index (S-CVI/Ave) was performed. The excellence of the content validity was assessed using generally accepted cut-off values ($\geq$0.78 I-CVI for $\geq$6 experts; $\geq$0.80 S-CVI/Ave).[26–29] To adjust for agreement by chance, the modified multi-rater Kappa (κ^*) was calculated. Cut-off values for κ^* were <0.40 for poor, $\geq$0.40 and <0.60 for fair, $\geq$0.60 and <0.75 for good, and $\geq$0.75 for excellent item relevance.[30,31]

Furthermore, the proportion of missing values for each item of the HBS-CHD was determined. This is a parameter of how intelligible an item is.[25]

Validity evidence based on relationships with other variables. Evidence based on relationships with other variables was evaluated by testing six hypotheses.[1,8–12] Population-based health behavior surveillance systems[18,32] and a study on health behaviors in individuals with CHD[9] showed that risky health behaviors are more prevalent in (emerging)

adults than in adolescents. Even within the groups of adolescents, increasing trends of health risk behaviors were observed.[32] This brought us to formulate the following three hypotheses:

> Hypothesis 1: The prevalence of substance use in adolescents and emerging adults with CHD is positively associated with increasing age.[9,32]
> Hypothesis 2: The prevalence of preventive dental hygiene in adolescents and emerging adults with CHD is negatively associated with increasing age.[9]
> Hypothesis 3: The prevalence of overall health-risk behaviors is positively associated with increasing age.[18,32]

Studies that compared health behaviors of patients with CHD and healthy controls showed better behaviors in patients with regard to the use of alcohol, illicit drugs and tobacco but worse behaviors in terms of dental practices.[1,8–10,12] Therefore, we formulated two hypotheses on the difference between patients and healthy controls:

> Hypothesis 4: The prevalence of substance use in adolescents and emerging adults with CHD is lower than that of controls from the general population.[1,8–10,12]
> Hypothesis 5: The prevalence of preventive dental hygiene in adolescents and emerging adults with CHD is lower than that of controls from the general population.[9,10]

Finally, we formulated a hypothesis regarding the relation between the Baecke's sport score[14] and the HBS-CHD physical exercise score. Although there is no gold standard in the self-report of physical activities, the Baecke questionnaire is well validated.[33,34] A good relationship between the Baecke sports score and the HBS-CHD physical exercise score, which calculation was based on the Baecke's algorithm, would support the validity evidence.

> Hypothesis 6: There is a high correlation (≥ 0.70) between the physical exercise score of the HBS-CHD and the Baecke's Sport Score.[14]

If the hypotheses are confirmed by empirical testing, the validity of the instrument under study is supported.[25,35]

Reliability evidence based on stability. For the evaluation of the stability of the HBS-CHD, a traditional test-retest is not applicable because behaviors are not stable in itself. Therefore, an alternative approach that is able to distinguish the stability of the concept (i.e. health behavior) from the stability of the tool (i.e. HBS-CHD) is used. We employed the technique as described by Heise (1969)[36,37] which requires four measurement points.

Responsiveness evidence. Responsiveness is "the ability of an instrument to record meaningful or clinically relevant changes in the patient's clinical state (e.g., health behavior) over time".[38] We assessed the internal responsiveness of the HBS-CHD, defined as " the ability of a measure to change over a predefined time frame".[39] Internal responsiveness can be evaluated with the use of a repeated measures design evaluating the changes in scale scores in a single sample of patients.[39] More specifically, we calculated Guyatt's Responsiveness Index (GRI).[40]

Study population for the hypothesis-testing, assessment of reliability and responsiveness

We examined the validity in relation with other variables, reliability and responsiveness of the HBS-CHD as part of a four-wave longitudinal project, spanning three years (at nine-month intervals): the i-DETACH project (Information technology Devices and Education program for Transitioning of Adolescents with Congenital Heart disease). Eligible patients were selected from the database of pediatric and congenital cardiology of the University Hospitals Leuven, Belgium. Patients were included if: they had a confirmed diagnosis of CHD, defined as structural abnormalities of the heart and/or great intrathoracic vessels that are actually or potentially of functional significance;[41] aged 14–18 years at the start of the study on 22 October 2009; last cardiac outpatient visit at our tertiary care center performed ≤ 5 years ago; being able to read and write Dutch; and the availability of valid contact details. Patients were excluded if they had cognitive and/or physical limitations that inhibited the ability of the patient to fill out questionnaires; if the patient previously underwent heart transplantation; and if patients and/or their parents did not consent to participation.

Overall, 498 patients met these criteria. A total of 429 adolescents (86%) participated in the first wave of the study; 398 patients (80%) partook in the second wave; and 363 patients (73%) completed the questionnaires in the third wave. In all, 348 participated in wave 1, 2, and 3. Wave 4 is currently still in progress. In June 2012, a total of 231 respondents had participated in the four subsequent waves.

At Wave 1, control subjects, comprising peers from the general population, were recruited at four secondary schools in two regions of Belgium. Matching (1:1) was performed, based on gender and age, resulting in 401 patients matched with a control subject (93.5%).

Measurements and procedure

Data were obtained using the HBS-CHD and a modified version of the Baecke questionnaire. The Baecke questionnaire is a self-report instrument assessing the habitual physical activity of adults,[14] which has been extensively used during the past two decades in physical activity research.[42,43] Although no gold standard for the self-report of physical

activity levels exists, the Baecke questionnaire was found to be a standard of reference that was validated against the double labeled water technique and a tri-axial accelerometer.[33,34] The Baecke questionnaire comprises three dimensions: (a) physical activity at work; (b) sports activity during leisure time; and (c) physical, non-sports activity during leisure time. Since our study respondents are all school-attending adolescents, we used a modified version of the Baecke questionnaire that collects data on leisure time and sport physical activity indices. For the purpose of the present study, we only used the Baecke Sport Score.

Each wave, all eligible adolescents with CHD received a package by surface mail, which included a set of questionnaires, an information letter, an informed consent form (for parents and adolescents), and a pre-stamped and addressed return envelope. To obtain a high response rate, a modified Dillman's approach was used.[44] More detailed information on this approach can be found in a related article.[45] The study was approved by the Institutional Review Board of the University Hospitals Leuven and the investigation was conducted in keeping with the principles outlined in the Declaration of Helsinki.[46]

Statistical analysis

To test the six hypotheses, we first calculated summary scores. A 'physical exercise score' was calculated based on the usual time (in hours) spent per week in various types of physical exercise, including the walk or bike ride to school or work (there and back), multiplied by the average energy expenditure per unit of time (MJ/h), as derived from Baecke.[14] This physical exercise score ranges from 0 to ∞, with higher scores indicating higher levels of physical exercise. Furthermore, the Baecke's Sport Score was calculated by multiplying the intensity of the practiced sport, the amount of time weekly playing that sport and the proportion of the year in which the sport was practiced.[14]

A 'substance use score', ranging from 0–3, was calculated based on the presence of (a) binge drinking at least monthly, (b) use of one or more of seven predefined drugs once a month or less, and (c) smoking of cigarettes. A 'dental hygiene risk score', varying between 0–3, was calculated based on the reporting that (a) the patient did not visit the dentist annually, (b) did not daily brush, and (c) did not floss his teeth. Finally, an 'overall health risk score' was computed based on the individuals' substance use score, dental hygiene risk score, and the absence of sport participation. This latter score ranges from 0–7. These latter three risk scores are recoded to a scale ranging from 0 (no risk) to 100 (maximum risk). In other words, a higher risk score represents a worse health behavior.

Statistical analyses were performed using SPSS version 17.0 (SPSS Inc., Chicago, Illinois, USA). Descriptive statistics of the three risk scores were expressed in terms of means and standard deviations for reasons of clarity and comparability. Differences in median risk scores between different age cohorts were tested using the non-parametric Jonckheere-Terpstra trend test. Intra-individual changes in median subscale scores over a period of 18 months were evaluated using the Friedman's test. Differences between patients and matched controls were tested using the McNemar test for nominal data and the Wilcoxon-signed rank test for ordinal data. To test the convergent validity of the HBS-CHD compared with the Baecke's questionnaire, we investigated the relationship between the HBS-CHD physical exercise score and the Baecke's Sport Score, both measured on a continuous scale, by calculating the Pearson's product moment correlation coefficient.

To test the stability of the HBS-CHD, we used the algorithms described by Heise[37] employing data of four measurement points. We calculated reliability and stability coefficients for the three risk scores: substance use risk score; dental hygiene risk score; and overall health risk score. The reliability coefficient of the instrument was calculated based on the equation:

$$r_{xx} = (r_{12} \times r_{23})/r_{13}$$

where the *r*s are the test-retest correlations.[37] To test the assumptions underlying this technique, the product of r_{14} and r_{23} must be very close to the product of r_{13} and r_{24}.[37]

To evaluate the internal responsiveness of the HBS-CHD, we calculated the GRI. This is the ratio of the minimally clinically important difference (i.e. a priori determined delta) divided by the root square of two times the mean squared error of the analysis of variance (ANOVA) for repeated measures.[39,40] We determined that a clinically significant change in health behavior is represented by one additional behavioral risk factor, reflecting a delta-value=1. Cut-off levels for the interpretation of the GRI are 0.20 for poor; 0.50 for moderate; 0.80 for good; and >1 for excellent responsiveness.[40]

Results

Sample characteristics

Adolescents with CHD in our sample had a median age of 16.3 years (Q1=15.3; Q3=17.3) (Table 1). The most common diagnosed heart defect was a ventricular septal defect (18.2%), followed by aortic valve abnormality (16.1%) and secundum atrial septal defect (13.1%). The majority of respondents had a moderately complex heart defect (47.6%), whereas mild and complex heart lesions were diagnosed in 40.6% and 11.9%, respectively. Additional details on sample characteristics can be found in Table 1.

Participants did not differ on sex (χ^2=0.163; *p*>0.05) and age (*U*=593.0; *p*>0.05) from non-participants. However, differences were found on complexity of CHD (*F*=9.255; *p*<0.05), with the group of non-responders having relatively more mild and fewer moderate congenital heart lesions.

Table 1. Demographic and clinical characteristics of adolescents with congenital heart disease (CHD) (*n*=429).

Variables	
Sex, *n* (%)	
Male	229 (53.4)
Female	200 (46.6)
Age (median; Q1–Q3)	16.3; 15.3–17.3
Primary diagnosis of CHD, *n* (%)	
Hypoplastic left-heart syndrome	2 (0.5)
Univentricular physiology	4 (0.9)
Tetralogy of Fallot	11 (2.6)
Double-outlet right ventricle	12 (2.8)
Double-inlet left ventricle	1 (0.2)
Truncus arteriosus	1 (0.2)
Transposition of the great arteries (TGA)	26 (6.1)
Congenitally-corrected TGA	5 (1.2)
Coarctation of the aorta	43 (10.0)
Atrioventricular septal defect	6 (1.4)
Atrial septal defect, type 1	4 (0.9)
Ebstein malformation	2 (0.5)
Pulmonary valve abnormality	38 (8.9)
Aortic valve abnormality	69 (16.1)
Aortic abnormality	9 (2.1)
Left ventricle outflow tract obstruction	5 (1.2)
Atrial septal defect, type 2	56 (13.1)
Ventricular septal defect	78 (18.2)
Mitral valve abnormality	37 (8.6)
Pulmonary vein abnormality	9 (2.1)
Other	11 (2.6)
Complexity of primary CHD diagnosis,[60]*n* (%)	
Complex	51 (11.9)
Moderate	204 (47.6)
Simple	174 (40.6)
Cardiac surgery for CHD, *n* (%)	
Yes, at least one cardiac surgical intervention	200 (53.4)
No	229 (46.6)
Current level of education, *n* (%)	
High school/College/University	194 (47.0)
Vocational high school	128 (31.0)
Technical high school	84 (20.3)
Education for adolescents with special needs	7 (1.7)

Content validity

Fourteen out of 22 (63.6%) HBS-CHD scale items were rated with an excellent content validity (I-CVI ≥0.78; $\kappa^* \geq 0.75$), and five other items (22.7%) were evaluated with a good content validity ($0.60 \leq \kappa^* < 0.75$). Two items ('11. Use of hallucinogenic mushrooms during last 12 months?' and '20. If yes, how long does it take by bike or on foot (there and back)?') obtained an I-CVI of 0.60 and a κ^* of 0.50, representing a fair content validity ($0.40 \leq \kappa^* < 0.60$). One item ('18. How often do you floss your teeth?') was evaluated as having a poor content validity (I-CVI=0.50;

κ^*=0.34). The S-CVI/Ave was 0.81 and the overall instrument's Kappa was 0.78, which reflects an adequate content validity.[26,29] If the three items with poor or fair content validity were removed from the scale, the S-CVI/Ave would increase to 0.85. However, because of clinical and theoretical considerations, these items were kept in the questionnaire to allow further analysis of the psychometric properties. The overall proportion of missing values over all scale items was low (1.2%). At item level, the proportion of missing values ranged from 0.0–5.3%. Questions regarding the frequency of flossing (5.3%) and brushing the teeth (3.9%) yielded the highest rate of missing values (Table 2).

Validity based on relationships with other variables

A comparison of the risk scores for substance use, dental hygiene and overall health risk, according to the age group, was performed (Table 3). In order to test the intra-individual evolution in risk scores over a period of 18 months, we compared these risk scores in adolescents with CHD (*n*=348) compared across wave 1, 2, and 3 (Table 4).

Data revealed that there is an increasing trend in substance use when adolescents with CHD are growing older (*Z*=3.71; *p*<0.001) (Table 3). During an 18-month interval, a significant intra-individual increase in substance use was found (χ^2=38.138; *p*<0.001) (Table 4). Hence, the first hypothesis can be confirmed.

The dental hygiene risk score increased in patients with CHD aged ≤16.9 years, but declined afterwards. Trend analysis showed no statistically significant evolution (*Z*= −1.32; *p*=0.19) (Table 3). Intra-individual comparisons confirmed that the dental hygiene risk score remained relatively stable over an 18-month period (χ^2=0.258; *p*=0.879) (Table 4). These results did not confirm our second hypothesis.

Analysis of the overall health risk scores demonstrated increased scores in patients until the age of 16.9 years, although this trend was not statistically significant (*Z*=1.37; *p*=0.17) (Table 3). Intra-individual analysis, however, showed a significant increase in the overall health risk of patients with CHD (χ^2=14.983; *p*=0.001). Thus, our third hypothesis could be supported.

Comparison of the prevalence of binge drinking (i.e. ≥6 glasses of alcohol during one occasion) between adolescents with CHD and matched controls from the general population, showed that significantly more controls performed binge drinking than patients with CHD (*p*<0.001) (Table 5). Furthermore, smoking of cigarettes and use of drugs during the past 12 months was significantly less prevalent in adolescents with CHD than peers (*p*<0.001). This corresponds with a significantly lower substance use score in patients

Table 2. Content validity: Analysis of item content validity index (I-CVI), modified multi-rater Kappa (κ*) and missing values.

Item of the HBS-CHD	I-CVI	κ*	Evaluation of κ*[30]	Missing values n (%)
1. Do you consume alcohol from time to time?	1.00	1.00	Excellent	0 (0.0)
1a. If yes, how often?	1.00	1.00	Excellent	0 (0.0)
2. When consuming alcohol, how many glasses do you have on average?	0.80	0.79	Excellent	0 (0.0)
3. How often do you drink six glasses or more on one occasion?	0.70	0.66	Good	3 (1.1)
4. Do you smoke cigarettes occasionally or regularly?	1.00	1.00	Excellent	1 (0.3)
5. During the last 30 days, on how many days did you smoke cigarettes?	0.70	0.66	Good	0 (0.0)
6. During the last 30 days, on the days you smoked, how many cigarettes did you smoke a day?	1.00	1.00	Excellent	0 (0.0)
7. How often, in the last 12 months, did you take the following drugs?	–	–	–	–
7a. Cannabis (marihuana, hash)	0.80	0.77	Excellent	7 (1.9)
7b. XTC	0.80	0.79	Excellent	10 (2.8)
7c. Cocaine	0.80	0.79	Excellent	10 (2.8)
7d. Hallucinogenic mushrooms	0.60	0.50	Fair	10 (2.8)
7e. Speed	0.80	0.79	Excellent	10 (2.8)
7f. Sleeping pills, sedatives or tranquilizers	0.70	0.66	Good	10 (2.8)
7g. Other drugs	0.70	0.66	Good	10 (2.8)
8. Have you been to the dentist in the past year?	1.00	1.00	Excellent	0 (0.0)
9. If not, when did you last go to the dentist?	0.90	0.90	Excellent	0 (0.0)
10. How often do you brush your teeth?	0.90	0.90	Excellent	14 (3.9)
11. How often do you floss your teeth?	0.50	0.34	Poor	19 (5.3)
12. Do you regularly walk or cycle to school or to your place of work?	0.70	0.66	Good	0 (0.0)
13. If yes, how long does it take by bike or on foot (there and back)?	0.60	0.50	Fair	1 (0.4)
14. Do you regularly practice a sport (this includes school sport but not the bike ride or walk to school or to your workplace)?	1.00	1.00	Excellent	1 (0.3)
15. During a 7-day week, how many hours of the following physical activities do you do?	0.90	0.90	Excellent	–
15a. Sports or activities that are very physically demanding, which increase your pulse (e.g. football, basketball …)	–	–	–	0 (0.0)
15b. Sports or activities that are moderately physically demanding and where, afterwards you don't feel exhausted or worn out (e.g. jogging, ballet…)	–	–	–	0 (0.0)
15c. Sports or activities with minimal physical effort or gentle exertions (e.g. golf, yoga…)	–	–	–	0 (0.0)
15d. Sport at school	–	–	–	0 (0.0)

XTC: ecstasy.

Table 3. Substance use, dental hygiene and health risk scores in adolescents with congenital heart disease (CHD) according to their age group (n=424).

Risk score	14–14.9 years (n=70)	15–15.9 years (n=105)	16–16.9 years (n=112)	17–18.9 years (n=137)	Test statistics
Substance use risk score on scale 0–100 ($\bar{x}\pm$SD)	0.96±8.00	5.70±18.76	8.32±20.28	8.72±19.06	Z=3.71; p<0.001
Dental hygiene risk score on scale 0–100 ($\bar{x}\pm$SD)	26.53±23.14	26.49±19.27	31.71±25.52	22.73±20.88	Z=−1.32; p=0.19
Total health risk score on scale 0–100 ($\bar{x}\pm$SD)	14.84±12.85	16.56±13.42	19.92±15.96	17.62±14.22	Z=1.37; p=0.17

SD: standard deviation; Z: Z-score for Jonckheere-Terpstra trend test.

than in matched controls (Z=–6.38; p<0.001). This corroborates the fourth hypothesis.

With regard to dental hygiene, more adolescents with CHD have an annual visit with their dentist than matched peers, although fewer patients report daily brushing of teeth or flossing of teeth. For the difference in flossing, statistical significance was reached (p<0.001). Furthermore, the dental hygiene risk score was significantly higher in patients with CHD compared to controls (Z=−2.05; p=0.04). Thus, the fifth hypothesis can be confirmed.

Finally, analysis showed the HBS-CHD physical exercise score to be significantly correlated with the Baecke's Sport

Table 4. Comparison of substance use, dental hygiene and health risk scores in adolescents with congenital heart disease (CHD), 18-month interval (*n*=348).

| Risk score	Wave 1	Wave 2	Wave 3	Test statistics
Substance use risk score on scale 0–100 ($\bar{x}$±SD)	5.41±16.39	7.91±18.71	11.10±22.65	χ^2=38.138; *p*<0.001
Dental hygiene risk score on scale 0–100 ($\bar{x}$±SD)	26.27±22.32	26.08±21.83	25.42±23.24	χ^2=0.258; *p*=0.879
Health risk score on scale 0–100 ($\bar{x}$±SD)	16.65±13.66	18.94±14.88	19.90±17.04	χ^2=14.953; *p*=0.001

SD: standard deviation.

Table 5. Comparison of prevalence of binge drinking, smoking of cigarettes, use of cannabis during past year and annual dental visits in adolescents with congenital heart disease (CHD) and peers from general population.

Health behavior	Patients with CHD	Matched controls from general population	Test statistics
Binge drinking[a]	30/401 (7.5%)	76/401 (19.0%)	*p*<0.001
Currently smoking cigarettes	27/399 (6.8%)	68/397 (17.1%)	*p*<0.001
Use of drugs during past 12 months	18/401 (4.5%)	63/401 (15.7%)	*p*<0.001
Visit to the dentist during past 12 months	359/401 (89.5%)	337/397 (84.9%)	*p*=0.061
Daily brushing of teeth	372/401 (92.8%)	383/401 (95.5%)	*p*=0.117
Flossing teeth	147/401 (36.7%)	214/401 (53.4%)	*p*<0.001
Substance use score($\bar{x}$±SD)	6.17±17.70	17.35±28.80	Z = −6.38; *p*<0.001
Dental hygiene score ($\bar{x}$±SD)	26.87±22.72	22.15±24.17	Z = −2.05; *p*=0.04
Health risk score ($\bar{x}$±SD)	17.34±14.46	27.85±17.36	Z = −8.51; *p*<0.001

SD: standard deviation.
[a]Binge drinking=drinking ≥6 glasses of alcohol on one occasion.[13,61]
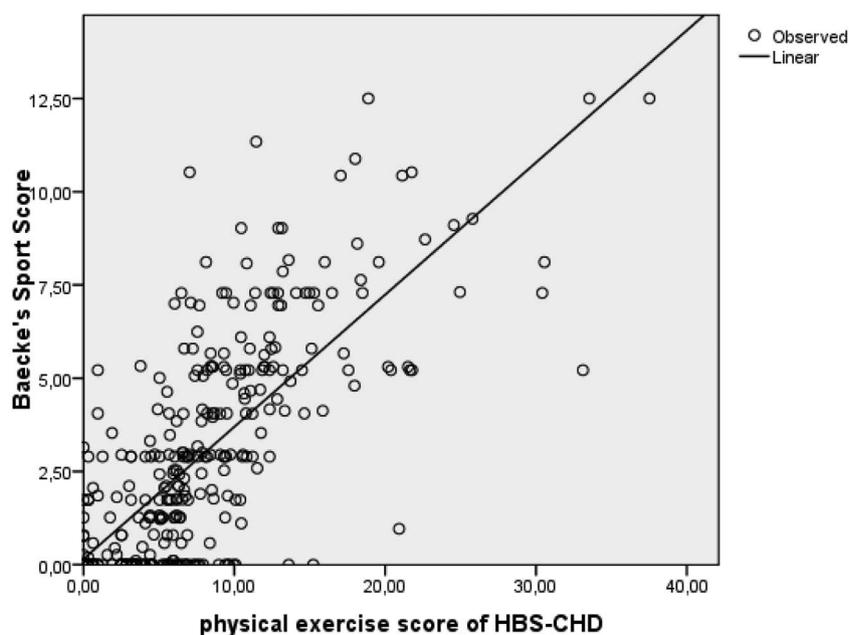
Figure 1. Scatterplot of Health Behavior Scale-Congenital Heart Disease (HBS-CHD) physical exercise score versus Baecke's Sport Score.

Score (Pearson's *r*=0.75; *p*<0.001) (Figure 1). This means that 56% of the variance (R^2) of the HBS-CHD physical exercise score could be explained by the Baecke's Sport Score. Therefore, our sixth hypothesis was confirmed.

Reliability based on stability

Using Heise's method,[37] we found a reliability coefficient of 1.08 for the substance use risk score; 0.37 for the dental hygiene risk score; and 0.57 for the overall health risk score. The underlying assumptions for this technique were violated for data on the substance use risk score, resulting in a coefficient >1. For the other two risk scores, the assumptions were fulfilled. The reliability coefficients were moderate to low. Based on these findings, the stability of the HBS-CHD over nine-month intervals could not be confirmed in the present study.

Responsiveness

The GRI was found to be 1.58 for the substance use risk score; 1.38 for the dental hygiene risk score; and 0.95 for the overall health risk score. This means that the HBS-CHD has a good to excellent capacity for detecting clinical changes in health behavior of patients with CHD over time.

Discussion

Although the importance of health-promoting and preventive behaviors in patients with CHD is well-established, a valid and comprehensive instrument to assess these behaviors is currently lacking. Therefore, we developed the comprehensive Health Behavior Scale-CHD scale (HBS-CHD), which relied in part on four existing questionnaires.[9,13–15,17–20] The use of the HBS-CHD allows to calculating four summary risk scores: physical exercise score; substance use risk score; dental hygiene risk score; and total health risk score. In order to use this scale in research and clinical practice, we evaluated some psychometric properties of the instrument.

Our study revealed that 19 of the 22 items (86.3%) of this scale had a good to excellent content validity. The overall scale content validity was found to be adequate since S-CVI/Ave was 0.81.[26,29] Two items received an I-CVI <0.60 and ≥0.40 which corresponds to a fair content validity. Four experts commented that the use of hallucinogenic mushrooms as a drug is rare in the Belgian population. Therefore, these experts rated this item as irrelevant. However, because we aimed at developing a comprehensive health behavior questionnaire that is also applicable in an international context, we wanted to keep this question in our scale. Indeed, the use of hallucinogenic mushrooms is more prevalent in other countries than in Belgium.[47] The second question, for which the relevance was found to be fair, concerned the duration of the bike ride or walk from home to school or work. Five experts rated this question as being not relevant but, unfortunately, gave no additional comments or suggestions. However, to be able to determine whether patients perform physical activities in accordance with general guidelines,[48] we prefer to keep this question in the HBS-CHD.

The relevance of one item was assessed to be poor: the frequency of flossing the teeth. The importance of excellent dental care in patients with CHD is well established. Several guidelines recommend annual visits to the dentist, daily brushing of teeth, and the administration of antibiotics prior to specific dental procedures as essential components to prevent infective endocarditis (IE).[49,50] The relationship between flossing teeth and IE is controversial.[49–56] On one hand, it is known that flossing may increase the occurrence of transient bacteremia, and thus may amplify the risk for IE.[57] On the other hand, teeth flossing is an essential element of good dental hygiene, which in its turn can avoid IE. In order to prevent the formation of caries, patients should brush their teeth daily and floss their teeth at least weekly.[55,58] Since the benefits of good dental hygiene, which includes interdental flossing, outweigh the risk for IE due to bacteremia, we keep this item in the HBS-CHD. Although none of the panel experts suggested adding additional items to the HBS-CHD, one could argue that our scale should also cover aspects of healthy eating and weight control as these are potential risk factors for the development of cardiovascular disease in cardiac patients.

Furthermore, analysis of the missing values showed that the average proportion of missing values was low. The proportion of missing values was somewhat higher only for the questions regarding the frequency of flossing and brushing the teeth. Hence, there is sufficient evidence to consider the content of the HBS-CHD as valid.

Validity evidence based on relationships with other variables was tested with six hypotheses. The first three hypotheses pertained to substance use, dental hygiene, and overall health risk behaviors, and their relationship with age. We analyzed differences in risk scores across four age groups, and investigated the intra-individual evolution in patients over an 18-month period. These results provided evidence for hypotheses 1 and 3. We did not find support to confirm hypothesis 2, regarding dental hygiene. Based on the comparison of the prevalence of binge drinking, smoking, use of drugs, and annual dental visits, the fourth and fifth hypotheses stating that substance use and preventive dental hygiene measures are less prevalent in adolescents with CHD compared to peers, were confirmed. Finally, our last hypothesis on the relationship between the HBS-CHD physical exercise score and the Baecke's Sport Score provided evidence for the convergent validity of the HBS-CHD. Since five out of six proposed hypotheses were confirmed, the validity of the HBS-CHD based on relationships with other variables was generally supported.

Analysis of the reliability coefficients using the method of Heise[37] revealed that we could not confirm the stability of the HBS-CHD over a nine-month period of time. We assume that the nine-month intervals that we used in our study design were not optimal in order to assess the stability of our scale. Hence, further research on the stability of the instrument is needed, in which shorter intervals between

the measurements are required. On the other hand, the responsiveness of this scale could be supported.

Methodological limitations

This study aimed to assess some psychometric properties of the HBS-CHD. We provided evidence to support the content validity and evidence on relationships with other variables of this scale. Other aspects of validity, such as validity on response processes; validity on internal structure; and predictive validity with respect to consequences, were not investigated. Assessing the validity based on response processes necessitates specific research designs. Indeed, participant's response processes could be evaluated using cognitive interviewing or observations during questionnaire completion.[25] The validity on the internal structure is traditionally investigated using factor analysis.[25,35] Several arguments were found against the use of exploratory factor analysis on the HBS-CHD scale. First, scale items are measured using several scale levels (e.g. nominal and ordinal data). Second, our scale comprises items aiming to screen patients for the use of alcohol, tobacco, etc. The use of these dichotomous items results in a large number of missing values for the sub-items when an item was not applicable to the patient. Factor analysis can only be performed on a dataset without missing values. Third, health behaviors are not necessarily interrelated (e.g. a patient who use alcohol does not necessarily use illicit drugs or smokes cigarettes), and a high frequency of alcohol consumption does not necessarily mean that the person drinks a high volume per occasion. Fourth, the analysis of a correlation matrix revealed that some items of our scale do not correlate with any other item; that a large number of items had a correlation coefficient <0.30; and that negative coefficients were observed. For all these reasons, the performance of exploratory factor analysis is not appropriate and not permitted on the HBS-CHD.

Assessment of the validity on the intended or unintended consequences[25] has limited relevance for validity testing of the HBS-CHD because its relevance lies more in educational and employment testing than in testing clinical phenomena.

For reliability, we evaluated the instrument's stability. Other aspects of reliability, such as interrater reliability and internal consistency,[25] were not tested. Since the HBS-CHD is a self-administered questionnaire, interrater reliability is not relevant. The same is true for the internal consistency. The items of the HBS-CHD are not supposed to measure one common concept. In addition, a Cronbach's alpha assumes that the items of the scale are correlated with each other at a level of 0.30 or above, because they are supposed to measure a common entity.[59] In order to check this assumption, a correlation matrix was constructed to examine the direction and magnitude of correlations between the items of the instrument. We found that a number of items did not correlate to any other item, and that negative correlations were found. Hence, the calculation of Cronbach's alpha is not appropriate and not permitted.

Conclusion

The HBS-CHD was developed as a brief questionnaire to assess the health risk behaviors of adolescents, emerging adults and adults with CHD. The present study provided evidence for the content validity and on relationships with other variables, and on the responsiveness of this instrument. We evaluated the HBS-CHD to be a valid and responsive instrument for its use in research and clinical practice, although further research on the instrument's stability is required.

Conflict of interest

The authors declare that there is no conflict of interest.

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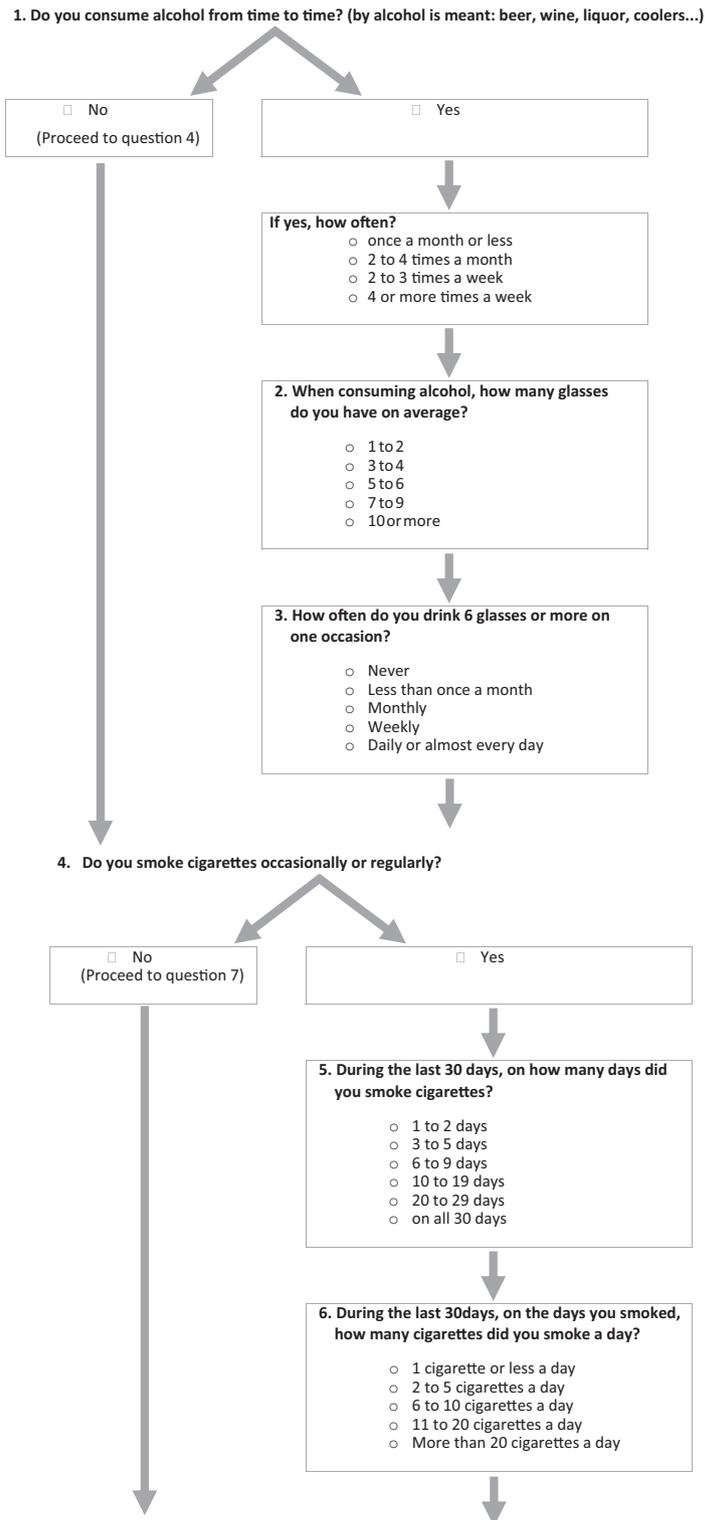
Appendix 1

Health Behavior Scale – Congenital Heart Disease – English (USA).

<u>Health behavior</u>

This questionnaire is about your health behavior. ***Colour*** the correct answer black.
Only *1 answer per question* please.

1. Do you consume alcohol from time to time? (by alcohol is meant: beer, wine, liquor, coolers...)

☐ No (Proceed to question 4)	☐ Yes

If yes, how often?
- ○ once a month or less
- ○ 2 to 4 times a month
- ○ 2 to 3 times a week
- ○ 4 or more times a week

2. When consuming alcohol, how many glasses do you have on average?
- ○ 1 to 2
- ○ 3 to 4
- ○ 5 to 6
- ○ 7 to 9
- ○ 10 or more

3. How often do you drink 6 glasses or more on one occasion?
- ○ Never
- ○ Less than once a month
- ○ Monthly
- ○ Weekly
- ○ Daily or almost every day

4. Do you smoke cigarettes occasionally or regularly?

☐ No (Proceed to question 7)	☐ Yes

5. During the last 30 days, on how many days did you smoke cigarettes?
- ○ 1 to 2 days
- ○ 3 to 5 days
- ○ 6 to 9 days
- ○ 10 to 19 days
- ○ 20 to 29 days
- ○ on all 30 days

6. During the last 30 days, on the days you smoked, how many cigarettes did you smoke a day?
- ○ 1 cigarette or less a day
- ○ 2 to 5 cigarettes a day
- ○ 6 to 10 cigarettes a day
- ○ 11 to 20 cigarettes a day
- ○ More than 20 cigarettes a day

7. How often, in the last 12 months, did you take the following drugs?

	Never	once a month or less	2 to 4 times a month	2 times or more a week
a. Cannabis (marihuana, hash)	○	○	○	○
b. XTC (ecstasy)	○	○	○	○
c. Cocaine	○	○	○	○
d. Hallucinogenic mushrooms	○	○	○	○
e. Speed	○	○	○	○
f. Sleeping pills, sedatives or tranquillizers	○	○	○	○
g. Other drugs:	○	○	○	○

8. Have you been to the dentist in the past year?

☐   No

☐   Yes
(Proceed to question 10)

9. If not, when did you last go to the dentist?

    ○   I never go to the dentist
    ○   1–2 years ago
    ○   2–3 years ago
    ○   More than 3 years ago

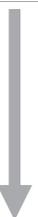**10. How often do you brush your teeth?**

    ○   I don't brush my teeth
    ○   I brush my teeth every now and then
    ○   once a day
    ○   twice a day
    ○   3 times a day
    ○   more than 3 times a day

11. How often do you floss your teeth?

    ○   I don't floss my teeth
    ○   I floss my teeth every now and then
    ○   once a day
    ○   twice a day
    ○   3 times a day
    ○   more than 3 times a day

12. Do you regularly walk or cycle to school or to your place of work?

| ☐   No
(Proceed to question 14) | ☐   Yes |

13. If yes, how long does it take by bike or on foot (there and back)?

- o   < 15 min
- o   15–30 min
- o   30–45 min
- o   > 45 min

14. Do you regularly practise a sport? (this includes school sports but <u>NOT</u> the bike ride or walk to school or to your workplace)

| ☐   No
(the questionnaire stops here; go to the next page) | ☐   Yes |

15. During a 7-day week, how many hours of the following physical activities do you do?

a.   <u>Sport at school</u>, during P.E. lessons or other sports periods

<div align="right">hours/week</div>

b.   Sports or activities that are <u>very physically demanding, which increase your pulse</u> (e.g. football, a long run, basketball, handball, korfball, squash, rowing, rugby, hockey, spinning, Thai boxing, kickboxing, cycle racing, rope-skipping, mountain biking, tennis,...)

<div align="right">hours/week</div>

c.   Sports or activities that are <u>moderately physically demanding</u> and where, afterwards, you <u>don't feel exhausted or worn out</u> (e.g. jogging, volleyball, swimming up and down, ballet, dancing, judo, karate, athletics, badminton, baseball, fitness classes, horse riding, wall climbing,...)

<div align="right">hours/week</div>

d.   Sports or activities with <u>minimal physical effort or gentle exertions</u> (e.g. billiards, ten-pin bowling, darts, golf, playing cards, yoga, fishing,...)

<div align="right">hours/week</div>