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Patient-Reported Outcomes of Health-Related Quality of Life in Children and Adolescents with Congenital Heart Disease

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Abstract

Background

To identify health-related quality of life (HRQOL) in children and adolescents with congenital heart disease (CHD) and to examine potential predictors of different outcome.

Methods

A total sample of 203 children and adolescents with CHD was recruited at our center. Data were collected using general information questionnaires, the Patient-Reported Outcomes Measurement Information System Pediatric-25 Profile (PROMIS-Profile 25), and the Patient-Reported Outcomes Measurement Information System Pediatric Short Form Sleep Disturbance 4a (PROMIS PSD4a). Latent profile analysis was conducted to identify distinct HRQOL subgroups. The Iterative Dichotomiser 3 (ID3) machine learning algorithm was then applied to predict profile membership based on participant characteristics.

Results

Univariate analysis revealed significant differences in patient-reported outcomes between simple and complex CHD, initial and staged operation patients. Two distinct HRQOL profiles were identified as "Well-adapted" type (69.46%) and "Maladapted type" (30.54%). The "Maladapted type" of children and adolescents with CHD scored significantly higher in the dimensions of anxiety, depressive symptoms, fatigue, pain, and sleep disturbance than the "Well-adapted type". The decision tree model revealed that age, monthly household income, and place of residence were significant predictors of different outcome.

Conclusions

HRQOL exhibited significant heterogeneity among children and adolescents with CHD. By recognizing these distinct profiles and their associated predictors, healthcare providers could better identify at-risk populations and implement personalized, life-course management strategies to improve HRQOL outcomes.

INTRODUCTION

Congenital heart disease (CHD) encompasses a spectrum of structural anomalies arising from aberrant embryonic development of the heart and great vessels, representing the most prevalent category of birth defects[1]. In China, the average prevalence has shown a marked upward trend[2]. As one of the most common chronic pediatric conditions, advances in cardiac surgery and interventional cardiology have substantially improved survival rates; however, enhanced longevity has not uniformly translated into favorable health-related quality of life (HRQOL)[3]. The current healthcare infrastructure remains inadequately equipped to address the complex, longitudinal needs of this growing population surviving to adolescence and adulthood. These needs extend beyond surgical surveillance to encompass comprehensive management of physical and psychosocial dysfunction, as well as long-term follow-up for major complications and chronic health sequelae.

The combination of physical function mobility, sedentary behavior, and sleep constitutes a critical determinant of health and well-being in children and adolescents[4]. Adequate physical function mobility is essential for maintaining optimal metabolic homeostasis and plays a fundamental role in social, emotional, and cognitive development[5]. Sedentary behavior, defined as waking activities characterized by sitting or reclining postures with low energy expenditure (≤ 1.5 metabolic equivalents), accounts for a substantial proportion (up to 80%) of waking hours across diverse environmental contexts[6]. The increasing propensity for sedentary pursuits has occurred in parallel with the rising prevalence of multiple chronic diseases and their associated complications. Sleep serves as a cornerstone for physical, mental, and social functioning during developmental stages.

Despite this established evidence, there remains a paucity of research examining the collective status of these three behavioral components among children and adolescents with chronic conditions, particularly those with CHD[7, 8]. Accordingly, we aim to use the Patient-Reported Outcomes Measurement Information System Pediatric-25 Profile (PROMIS-Profile 25) and the Patient-Reported Outcomes Measurement Information System Pediatric Short Form Sleep Disturbance 4a (PROMIS PSD4a) as robust instruments for capturing children's holistic life experiences to comprehensively assess the HRQOL of children and adolescents with CHD.

METHODS

1.1 Study Population

From July 2024 to August 2025, children and adolescents with CHD and their families who were treated at our center were investigated using convenience sampling. Inclusion criteria: (1) Children and adolescents with CHD aged 5–17 years; (2) Children and adolescents and their primary caregivers agreed to participate in this study. To guarantee procedural standardization and data integrity, all questionnaires were administered under the guidance of trained research staff. In this setting, children aged 8 and above participated independently, whereas those aged 5–8 were assisted by their primary caregivers. Exclusion criteria: (1) Those with other major concomitant diseases; (2) Those with communication difficulties.

Decision tree model analysis typically requires a sample size of 5–10 times the number of independent variables. This study included 12 independent variables, and considering a 20% invalid questionnaire rate, the calculated sample size was 150 cases. A total of 221 children and adolescents and their families were actually followed up, and 203 questionnaires were finally completed, resulting in an effective recovery rate of 91.86%.

1.2 Survey Instruments

1.2.1 General Information

General information included patients' sex, age, height, weight, education level, diagnosis, and number of surgeries. Family information included parents' educational level, place of family residence, family type, monthly household income, and medical payment method.

1.2.2 Assessment of Nutritional Status

Children's nutritional status was evaluated by BMI-for-age; those with a BMI-for-age percentile below the 5th were classified as at risk of malnutrition[9].

1.2.3 PROMIS-Profile 25

The PROMIS-Profile 25 is a comprehensive tool for assessing HRQOL across six domains relevant to chronic conditions[10]. It comprises 25 items covering Anxiety, Depressive Symptoms, Fatigue, Pain Interference, Physical Function (Mobility), Peer Relationships, and Pain Intensity. Pain Intensity is rated on a 0–10 numerical scale, while all other items use a 5-point Likert scale. For the 2 functional domains (Physical Function and Peer Relationships), higher scores reflect better functioning; for the 4 symptom domains (Anxiety, Depressive Symptoms, Fatigue, and Pain Interference), higher scores indicate greater symptom burden. Scoring involves transforming the sum of the 4 items in each domain into a standardized T-score (mean = 50, SD = 10). A 5-point difference is considered clinically meaningful. T-scores above 45 for Anxiety, Depressive Symptoms, Fatigue, and Pain Interference, or below 55 for Physical Function and Peer Relationships, suggest poor health status. All items are drawn from validated PROMIS pediatric item banks and are confirmed for use in pediatric populations[11].

1.2.4 PROMIS PSD4a

The PROMIS PSD4a is a self-report instrument designed to assess sleep disturbance in children and adolescents over the previous 7 days, focusing on sleep efficiency and subjective sleep quality. The measure consists of 4 items, and the total raw score is transformed into a standardized T-score. Developed using rigorous PROMIS mixed-methods methodology, the scale demonstrates strong reliability and validity in both community and clinical samples, and has been validated against established pediatric sleep measures. A T-score of 50 represents the mean for the reported pediatric population, while a score of 65.5 or higher indicates severe sleep disturbance[12].

1.3 Data Collection Method

In this study, trained researchers conducted face-to-face questionnaire surveys with all eligible children, adolescents, and their families at the CHD follow-up clinic of the cardiac center. Prior to the survey, the researchers explained the purpose, significance, and completion guidelines in detail, emphasizing that participation was voluntary. Informed consent was obtained from all legal guardians. After obtaining informed consent, the researchers guided participants through the questionnaire following standardized procedures. The study protocol was approved by the Ethics Committee of Shanghai Children's Medical Center (Ethics approval number: SCMCIRB-K2023211-1). All methods were performed in accordance with the relevant guidelines and regulations.

1.4 Statistical Methods

Data analysis was performed using SPSS 27.0 software. Continuous variables were presented as mean ± standard deviation (M ± SD) for normally distributed data, and inter-group comparisons were conducted using independent samples t-tests. Non-normally distributed continuous variables were expressed as median and interquartile range [M (IQR)], with group comparisons performed using the Mann–Whitney U test. Categorical variables were reported as counts and percentages [n (%)], and comparisons between groups were made using the chi-squared test or Fisher's exact test, as appropriate.

Latent class analysis was conducted using R software. The number of latent classes was progressively increased starting from a one-class model. The optimal class solution was determined based on model fit indices and classification quality. Fit indices included the Akaike Information Criterion (AIC), Bayesian Information Criterion (BIC), Consistent Akaike Information Criterion (CAIC), and adjusted Bayesian Information Criterion (BIC), with lower values indicating better model fit. Classification accuracy was evaluated using entropy, where values closer to 1 indicate clearer class delineation. The bootstrap likelihood ratio test (BLRT) was used to compare nested models, with a P value < 0.05 indicating that the k-class model provided a significantly better fit than the (k-1)-class model.

When the number of latent classes was set to 2, the BIC was 10942.70, and the BLRT yielded a P value of < 0.01. When a three-class model was specified, the BIC decreased slightly; however, the entropy value remained nearly unchanged, and the class probabilities included a value of 0.079. For the four- and five-class models, the change in BIC was minimal, while the entropy value showed a marked deviation from 1. Based on a comprehensive evaluation of model fit indices and classification interpretability, the two-class solution was identified as the optimal model (Supplementary Table 1).

A decision tree model was constructed using the Iterative Dichotomiser 3 (ID3) algorithm, a machine learning method that selects split nodes based on the principle of maximum information gain. This model was employed to predict the HRQOL typology across different latent classes. All statistical tests were two-tailed, and a P value < 0.05 was considered statistically significant.

RESULTS

2.1 General Characteristics of Children and Adolescents with CHD and Factors Affecting their HRQOL

The study included children and adolescents with CHD, with a mean age of 10.19 ± 2.67 years. The group comprised 104 boys (51.23%), 174 primary school students (85.71%), and 24 cases (11.82%) identified as at risk of malnutrition. A total of 63 participants (31.03%) had complex CHD, and 47 (23.15%) had undergone surgical intervention. Sixty-nine families (33.99%) reported a monthly household income exceeding 10,000 RMB, and 63 participants (31.00%) resided in rural areas (Table 1).

Table 1
General characteristics among the participants[n(%)//M(IQR)].

Variable	n(%)/$\varvec{\bar{X} \pm S}$ (n=203)
Age	10.19 ± 2.67
Gender	
Male	104 (51.23)
Female	99 (48.77)
Nutritional status	
No risk of malnutrition	179 (88.18)
At risk of malnutrition	24 (11.82)
Diagnosis	
Simple CHD	140 (68.97)
Complex CHD	63 (31.03)
Surgical status	
Initial operation	156 (76.85)
Staged operation	47 (23.15)
Educational level	
Primary school	174 (85.71)
High school	29 (14.29)
Place of residence	
Urban	140 (69.00)
Rural	63 (31.00)
Father's educational level	
High school or below	99 (48.77)
College or above	104 (51.23)
Mother's educational level	
High school or below	89(43.84)
College or above	114(56.16)
Family type	
Nuclear family	187 (92.12)
Extended family	9 (4.43)
Reconstituted family	3 (1.48)
Single-parent family	4 (1.97)
Monthly household income (RMB)	
> 20000	24 (11.82)
10001–20000	45 (22.17)
5000–10000	89 (43.84)
< 5000	45 (22.17)
Medical payment method	

Variable	n(%)/$\varvec{\bar{X}} \pm \varvec{S}$(n=203)
Medical insurance	167(82.26)
Self-pay	9(4.43)
Other	27(13.30)

Univariate analysis revealed significant differences in patient-reported outcomes based on clinical and demographic characteristics. Boys with CHD reported more severe depressive symptoms and greater pain interference than girls. Compared to those with simple CHD, children and adolescents with complex CHD exhibited significantly higher levels of anxiety, depressive symptoms, fatigue, and pain interference, as well as greater impairment in physical functioning and peer relationships. Similarly, participants who had undergone surgery reported more severe anxiety, depressive symptoms, fatigue and pain interference, along with more pronounced impairment in peer relationships, relative to those who had not undergone surgery (Table 2).

Table 2
HRQOL Differences Between different subgroup of CHD: T-test Results in Children and Adolescents.

Domain	Male (n = 104)	Female (n = 99)	t/Z	P	Simple CHD (n = 140)	Complex CHD (n = 63)	t/Z	P	Initial operation (n = 156)	Staged operation (n = 47)	t/Z	P
PROMIS-Profile 25												
Anxiety	44.37 ± 9.67	42.39 ± 9.17	1.495	0.136	42.34 ± 8.62	45.76 ± 10.81	-2.213	0.029	42.41 ± 8.95	46.70 ± 10.42	-2.553	0.013
Depressive Symptoms	43.56 ± 7.75	41.57 ± 6.38	2.001	0.047	41.66 ± 6.27	44.65 ± 8.53	-2.491	0.014	41.92 ± 6.79	44.82 ± 7.96	-2.267	0.027
Fatigue	44.53 ± 9.75	42.17 ± 8.42	1.845	0.067	41.93 ± 8.30	46.60 ± 10.24	-3.184	0.002	42.40 ± 8.84	46.63 ± 9.63	-2.815	0.005
Pain Interference	43.69 ± 9.20	40.78 ± 7.04	2.533	0.012	41.40 ± 7.93	44.21 ± 8.90	-2.250	0.026	41.23 ± 7.51	45.71 ± 9.95	-2.848	0.006
Physical Function Mobility	48.58 ± 9.34	48.16 ± 10.32	0.303	0.762	49.52 ± 9.69	45.81 ± 9.65	2.526	0.012	1.00(2.00)	1.00(4.00)	1.700	0.089
Peer Relationships	52.22 ± 10.59	53.69 ± 10.16	-1.011	0.313	54.29 ± 9.74	49.93 ± 11.19	2.812	0.005	49.08 ± 9.90	46.02 ± 9.20	1.890	0.060
PROMIS PSD4a	54.43 ± 4.81	53.87 ± 5.60	0.757	0.450	53.95 ± 5.38	54.62 ± 4.74	-0.848	0.397	53.95 ± 10.07	49.58 ± 10.82	2.563	0.011
Sedentary Behavior (h)	10.07 ± 4.91	10.75 ± 5.47	-0.939	0.349	10.25 ± 5.00	10.73 ± 5.61	-0.603	0.547	53.94 ± 5.20	54.90 ± 5.13	-1.112	0.268

2.2 Results of Latent Profile Analysis of HRQOL in Children and Adolescents with CHD

The two latent profiles were characterized based on scores from the PROMIS-Profile 25 dimensions, the PROMIS PSD4a, and sedentary behavior time (Table 3).

Table 3
Results of Latent Profile Analysis of HRQOL in Children and Adolescents with CHD.

Variable	Well-adapted type (n = 141)	Maladapted type (n = 62)	Test statistic	*P* value
PROMIS-Profile 25				
Anxiety	39.64 ± 7.60	51.96 ± 7.53	-10.669[a]	< 0.001
Depressive Symptoms	38.16 ± 1.70	52.67 ± 3.84	-28.536[a]	< 0.001
Fatigue	39.47 ± 7.12	52.27 ± 6.87	-11.914[a]	< 0.001
Pain Interference	39.83 ± 6.98	47.82 ± 8.54	-6.475[a]	< 0.001
Physical Function Mobility	49.67 ± 9.52	45.43 ± 9.89	2.890[a]	0.004
Peer Relationships	55.72 ± 9.42	46.60 ± 9.73	6.287[a]	< 0.001
PROMIS PSD4a	53.39 ± 5.66	55.91 ± 3.37	-3.259[a]	0.001
Sedentary Behavior (h)	10.00(6.00)	8.00(7.00)	-2.212[d]	0.027

Category 1 (Well-adapted type): Children and adolescents in this profile exhibited lower scores across symptom domains (Anxiety, Depressive Symptoms, Fatigue, and Pain Interference) and higher scores on functional domains (Physical Function and Peer Relationships) of the PROMIS-Profile 25. They also reported low sleep disturbance scores and slightly longer sedentary behavior time. This category comprised 141 participants, accounting for 69.46%.

Category 2 (Maladapted type): This profile was characterized by higher scores on symptom dimensions and lower scores on functional dimensions of the PROMIS-Profile 25. Participants in this group also had elevated sleep disturbance scores and slightly shorter sedentary behavior time. This category included 62 participants, representing 30.54%.

The distribution and distinguishing features of the two latent profiles were illustrated in Fig. 1.

2.3 Univariate Analysis of Latent Profiles of HRQOL in Children and Adolescents with CHD

Univariate analysis revealed significant between-group differences in age, diagnosis, surgical status, and educational level of both the children and their parents ($P < 0.05$) (Table 4). Specifically, children in the maladapted group were older, more likely to have complex CHD and postoperative status, and had parents with lower educational attainment. No significant differences were observed for gender, nutritional status, or socioeconomic indicators such as residence, family type, income, or payment method ($P > 0.05$).

Table 4

Univariate analysis of latent profiles of quality of life among the participants[n(%)/$\varvec{X} \pm \varvec{S}$ /M(IQR)].

Variable	Well-adapted type (n = 141)	Maladapted type (n = 62)	Test statistic	*P* value
Age	9.79 ± 2.28	11.10 ± 3.25	-2.860[a]	0.005
Gender			1.298[b]	0.255
Male	68 (48.23)	36 (58.06)		
Female	73 (51.77)	26 (41.94)		
Nutritional status			0.153[b]	0.695
No risk of malnutrition	123 (87.23)	56 (90.32)		
At risk of malnutrition	18 (12.77)	6 (9.68)		
Diagnosis			4.250[b]	0.039
Simple CHD	104 (73.76)	36 (58.06)		
Complex CHD	37 (26.24)	26 (41.94)		
Surgical status			4.929[b]	0.026
Initial operation	115 (81.56)	41 (66.13)		
Staged operation	26 (18.44)	21 (33.87)		
Educational level			11.077[b]	< 0.001
Primary school	129 (91.49)	45 (72.58)		
High school	12 (8.51)	17 (27.42)		
Place of residence			1.152[b]	0.283
Urban	101 (71.63)	39 (62.90)		
Rural	40 (28.37)	23 (37.10)		
Father's educational level			4.904[b]	0.027
High school or below	61 (43.26)	38 (61.29)		
College or above	80 (56.74)	24 (38.71)		
Mother's educational level			6.525[b]	0.011
High school or below	53 (37.59)	36 (58.06)		
College or above	88 (62.41)	26 (41.94)		
Family type			2.260[c]	0.528
Nuclear family	132 (93.62)	55 (88.71)		
Extended family	5 (3.55)	4 (6.45)		
Reconstituted family	2 (1.42)	1 (1.61)		
Single-parent family	2 (1.42)	2 (3.23)		
Monthly household income (RMB)			1.713[b]	0.634
> 20000	16 (11.35)	8 (12.90)		
10001–20000	30 (21.28)	15 (24.19)		

Variable	Well-adapted type (n = 141)	Maladapted type (n = 62)	Test statistic	*P* value
5000–10000	66 (46.81)	23 (37.10)		
< 5000	29 (20.57)	16 (25.81)		
Medical payment method			8.460[c]	0.058
Medical insurance	116 (82.27)	51 (82.26)		
Self-pay	3 (2.13)	6 (9.68)		
Other	22 (15.61)	5 (8.06)		

2.4 Prediction Model for Different Latent Profile Typologies of HRQOL in Children and Adolescents with CHD

The decision tree model identified age as the root node. Children and adolescents with CHD under 13 years of age were classified as the "Well-adapted type." This subgroup constituted 84% of the total sample, with a predicted probability of 75% for the "Well-adapted type" and 25% for the "Maladapted type" (Fig. 2).

Monthly household income and place of residence served as internal nodes. Among participants aged 13 years or older, those with a monthly household income exceeding 10,000 RMB were classified as the "Maladapted type." Within the same age group and among those with a monthly household income of ≤ 10,000 RMB, individuals residing in rural areas were also predicted to be the "Maladapted type." Detailed classification probabilities for each node were presented in Fig. 2.

DISCUSSION

Based on the Patient-Reported Outcomes Measurement Information System for children, this study employed latent profile analysis to identify heterogeneity in quality of life among children and adolescents with CHD. Two distinct profiles emerged: the "Well-adapted type" (69.46%) and the "Maladapted type" (30.54%). Approximately one-third of participants exhibited elevated symptoms of anxiety, depression, fatigue, and pain interference (mean T-scores all > 45), along with varying degrees of impairment in physical function, peer relationships (mean T-scores all < 55), and sleep disturbance. These findings indicated that, compared with the general healthy population, children and adolescents with CHD experience significantly compromised physical and mental health, as well as reduced overall quality of life[13]. Despite therapeutic advancements and prolonged survival, HRQOL among this population remains notably stratified. These results underscore the need for continued attention to the physiological and psychosocial well-being of those classified as the "Maladapted type."

The "Maladapted type" of children and adolescents with CHD scored significantly higher in the dimensions of anxiety, depressive symptoms, fatigue, pain, and sleep disturbance than the "Well-adapted type", but scored significantly lower in physical function and peer relationships. This suggested that symptom experiences perceived by children and adolescents could identify different latent profiles of HRQOL outcomes, especially mental health problems. A cohort study based on the Danish population showed that the cumulative incidence of mental health problems in the CHD cohort at age 18 was 35.1%, with distinct peaks in early childhood and adolescence[14]. These mental health problems are often accompanied by restricted physical activity, exercise, and social participation, and persist into adulthood[15, 16]. Of note, the median sedentary behavior time in the "Well-adapted type" and "Maladapted type" children and adolescents in this study were 10 and 8 hours per day, respectively, both significantly exceeding the ≤ 2 hours per day recommendation proposed by the Canadian (2016) and Australian (2019) 24-Hour Movement Guidelines for Children and Adolescents[17, 18]. Therefore, healthcare providers should focus on the mental health of children with CHD early on, develop individualized activity and exercise plans, and provide continuous support during their transition from the pediatric to the adult environment.

The decision tree analysis identified age as the primary predictor differentiating latent HRQOL profiles among children and adolescents with CHD. Those under 13 years of age were predominantly classified as the "Well-adapted type," whereas participants aged 13 years and older were more likely to exhibit the "Maladapted type." This finding aligned with previous research indicating that older children reported significantly lower self-rated quality of life[19]. Two explanations may account for this pattern. First, functional deficits in domains such as language, motor skills, and socioemotional development—which may accompany CHD—tend to become more pronounced with age[20]. Second, as older children and adolescents develop greater capacity for self-management, family oversight of health-related behaviors and HRQOL management may diminish[21].

Household monthly income and place of residence also emerged as important predictors. Among lower-income families (≤ 10,000 RMB per month), 70% of children and adolescents residing in rural areas were classified as the "Maladapted type," suggesting that financial constraints

and limited access to resources may hinder participation in continuous cardiac rehabilitation and psychological support services. Even in countries with universal healthcare, maintaining continuity of postoperative follow-up for CHD remains a global challenge[3]. In contrast, among higher-income families (> 10,000 RMB per month), the proportion of participants aged ≥ 13 years classified as the "Maladapted type" increased to 90%. This may reflect heightened psychological stress related to social comparison, academic pressure, and achievement expectations among adolescents from high-income backgrounds, pointing to a potential "bimodal differentiation" in HRQOL outcomes within this subgroup[22].

These findings underscore the need for tailored interventions that prioritize older adolescents with CHD and account for family socioeconomic context in designing support strategies.

This study employed a cross-sectional design, which inherently limited the ability to infer causality. During the investigation period, there was a notable imbalance in sample size between children and adolescents who had not undergone surgery and those who had (156 vs. 47). In addition, individual differences in cognitive function among younger participants may introduce some degree of response bias. Future research should aim to include multi-center, large-sample populations and adopt longitudinal study designs to better capture long-term changes in quality of life and to support precise, life-course management of individuals with CHD.

The HRQOL among children and adolescents with CHD demonstrated notable group heterogeneity, with age, monthly household income, and place of residence emerging as key predictive factors. The "Maladapted type" of children and adolescents with CHD scored significantly higher in the dimensions of anxiety, depressive symptoms, fatigue, pain, and sleep disturbance than the "Well-adapted type". Healthcare providers should identify high-risk populations based on the characteristics and determinants of distinct subgroups, and implement individualized prevention and intervention strategies to support their smooth transition into adulthood.

Declarations

Conflict of Interest

The authors declare that they have no competing interests.

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Data Availability Statements

The data that support the findings of this study were not openly available due to reasons of sensitivity and were available from the corresponding author upon reasonable request. Data were located in controlled access data storage at Shanghai Children's Medical Center.

Author contributions

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Figures

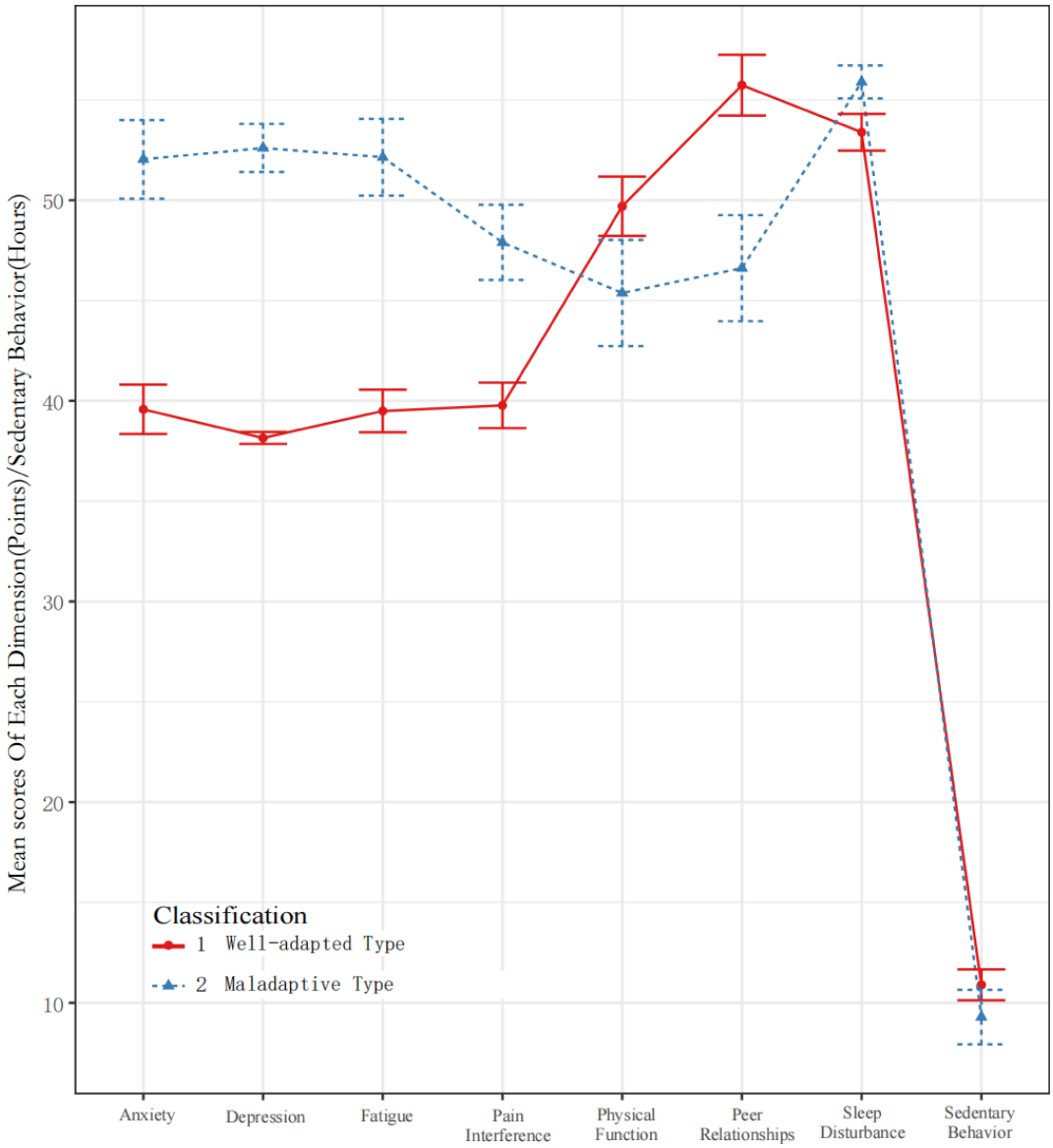


Figure 1

Latent profile analysis of HRQOL among children and adolescents with CHD.

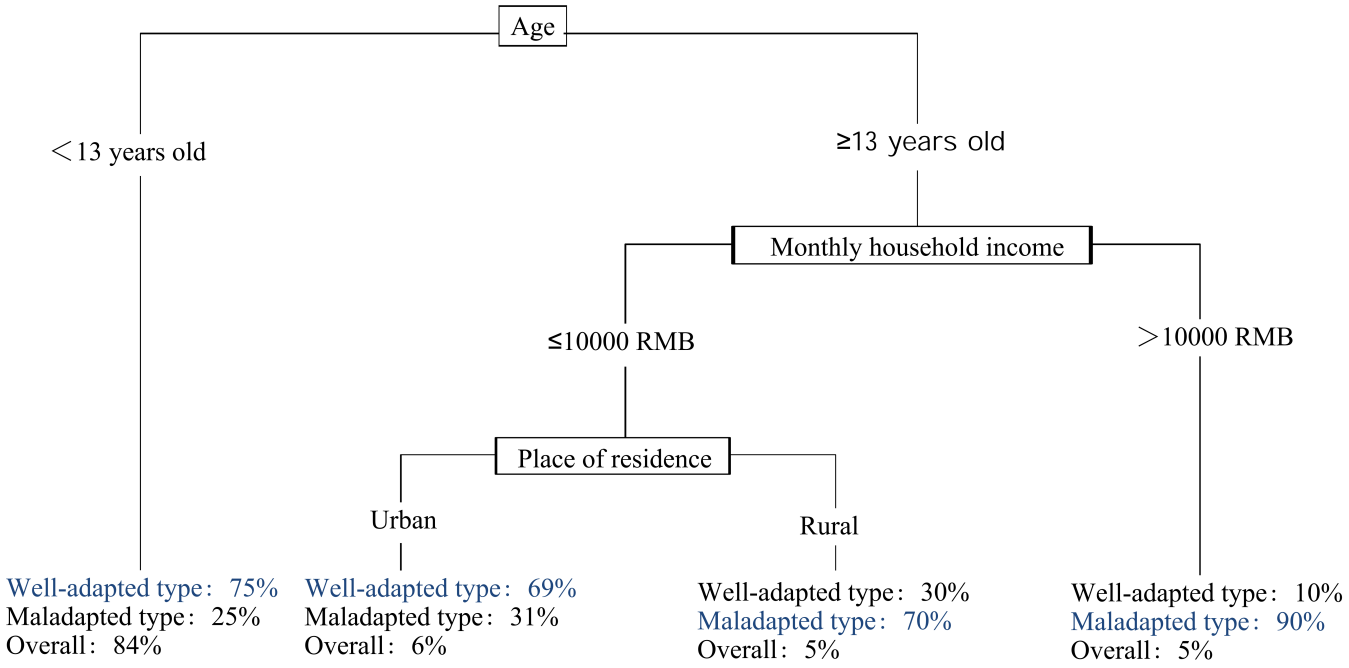


Figure 2

Decision tree model of quality of life among children and adolescents with CHD.

Supplementary Files

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- SupplementaryTable1.docx