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Psychosocial assessment and quality of life assessment in children with congenital heart in a developing country

Aly Abdel Mohsen, Mona Gamal Kassem and Manal A.-M. Antonios*

Abstract

Background: Few studies have examined the clinical utility of a brief psychosocial screening questionnaire and assessing the health-related quality of life as part of routine care in a pediatric cardiology clinic.

Subject and methods: A cross-sectional study was conducted over 6 months duration involving 224 patients with congenital heart diseases (CHD) aged 4–18 years and their parents to fulfill Pediatric Symptom Checklist (PSC) and Health related – Quality Of Life (HR-QOL) score. Statistical analysis of reliability of these scores among the studied population was carried using Cronbach's alpha value.

Results: The studied population with CHD, aged 4–18 years with a mean \pm standard deviation of 99.48 ± 43.37 months. They were 54.5% males ($n = 122$) and 45.5% females ($n = 102$). Internalizing problems were identified by PSC in 12.95% of patients ($n = 29$), Cyanosis was found to be the only significant independent risk factor for developing internalizing defects ($p < 0.001$). Quality of school functioning was the most affected domain in HR-QOL. While, the quality of social functioning remained good in the majority of cases. Cronbach's alpha value coefficient of PSC and HR-QOL scores were 0.846 and 0.900 respectively, reflecting good to excellent reliability of these scores within the studied population.

Conclusions: Children with CHD have increased need for psychosocial assessment for improvement of their quality of life.

Keywords: Psychosocial assessment, PSC, Quality of life, Congenital heart diseases

Background

Nowadays, 90% of newborns diagnosed with congenital heart diseases (CHD) live to adulthood [1]. As survival rates improved, psychosocial issues have emerged as a critical research area [2]. The question of how best to identify children and families who could benefit from psychology support is crucial, given the limited psychology resources [3]. Systematic psychosocial screening processes have been implemented in primary-care settings [4]. Jellinek et al [5] have created the Pediatric Symptom

Checklist (PSC) questionnaire to identify children with difficulties in psychosocial functioning, PSC is not a diagnostic tool, but indicates that children with positive results would benefit from further evaluation [6]. Moreover, the evaluation of Quality Of Life (QOL) provides a comprehensive description of the health of the individual in relation to physical, functional and psychosocial dysfunctions and is an important component in assessing the long-term impact of chronic conditions [7]. Health Related-quality of life (HR-QOL) tool is an assessment of how individual well-being may be affected over time by a disease or disability [8]. To date, studies on QOL in CHD patients reported contradictory findings: some studies reported poorer QOL related to cardiac instability and

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disease severity [9], while others concluded that CHD patients had better QOL than healthy people [10].

In developing countries, there is lack of interest in the psychosocial impact of chronic disease and its effect on QOL.

Aims of the study

This study aimed to assess the psychosocial aspect and quality of life of children with stable congenital heart disease and to check the validity of the screening tools used among the studied population.

Methods

A cross-sectional study was designed to screen pediatric patients with CHD coming for follow-up in the cardiology clinic of a tertiary care level hospital affiliated to a university in a developing country. Included patients aged 4–18 years should have their diagnosis confirmed by a 10-year expert echo-cardiographer. Patients having associated other congenital malformations, genetic syndromes, or neurologic or mental handicaps were excluded. After explaining the benefit of the study to parents or care-givers of the patients, an informed written consent was obtained for the purpose of publication. After initial data entry, included cases were asked to fulfill the PSC [11], which consists of 35 questions some of them were addressed to the patient, others were addressed to the parents or caregivers because parents are often the first to notice a problem with the child's behavior or emotions even before the child himself. For each item a score of 0, 1, or 2 is provided, then a total score for all 35 items is calculated. The PSC score includes 3 domains of psychological assessment: attention, internalizing, and externalizing subscales. Each subscale consists of a set of questions that represent a tool of diagnosing the patient readiness to suffer from a psychiatric disturbance. An attention positive subscale points to possible attention deficit hyperactivity disorders, internalizing subscale positive refers to possible depression disorders, and finally externalizing subscale positive refers to possible conduct disorders. Then, the HR-QOL score [12] consisting of 23 questions divided into 4 main sections: problems with physical functioning (8 questions), problems with emotional, social, and school functioning (5 questions each). For each item, a score of 0–4 is recorded. In the present study, patients aged 4–8 years, their HR-QOL score was answered by the parents or caregivers only, patients aged 8–12 years were involved in the assessment along with their parents and they discussed together before choosing the appropriate scores. Finally, patients aged 13–18 years answered the HR-QOL score alone with no interference from their parents. For each section, results were stratified into poor, fair, good,

and excellent according to the interpretation of the QOL score: < 25%, 25–50%, 50–75%, and \geq 75%, respectively.

A sample size of 220 patients was calculated to evaluate PSC, HR-QOL scores with a statistical power of 80% and statistical significance less than 5% [13].

Statistical consideration

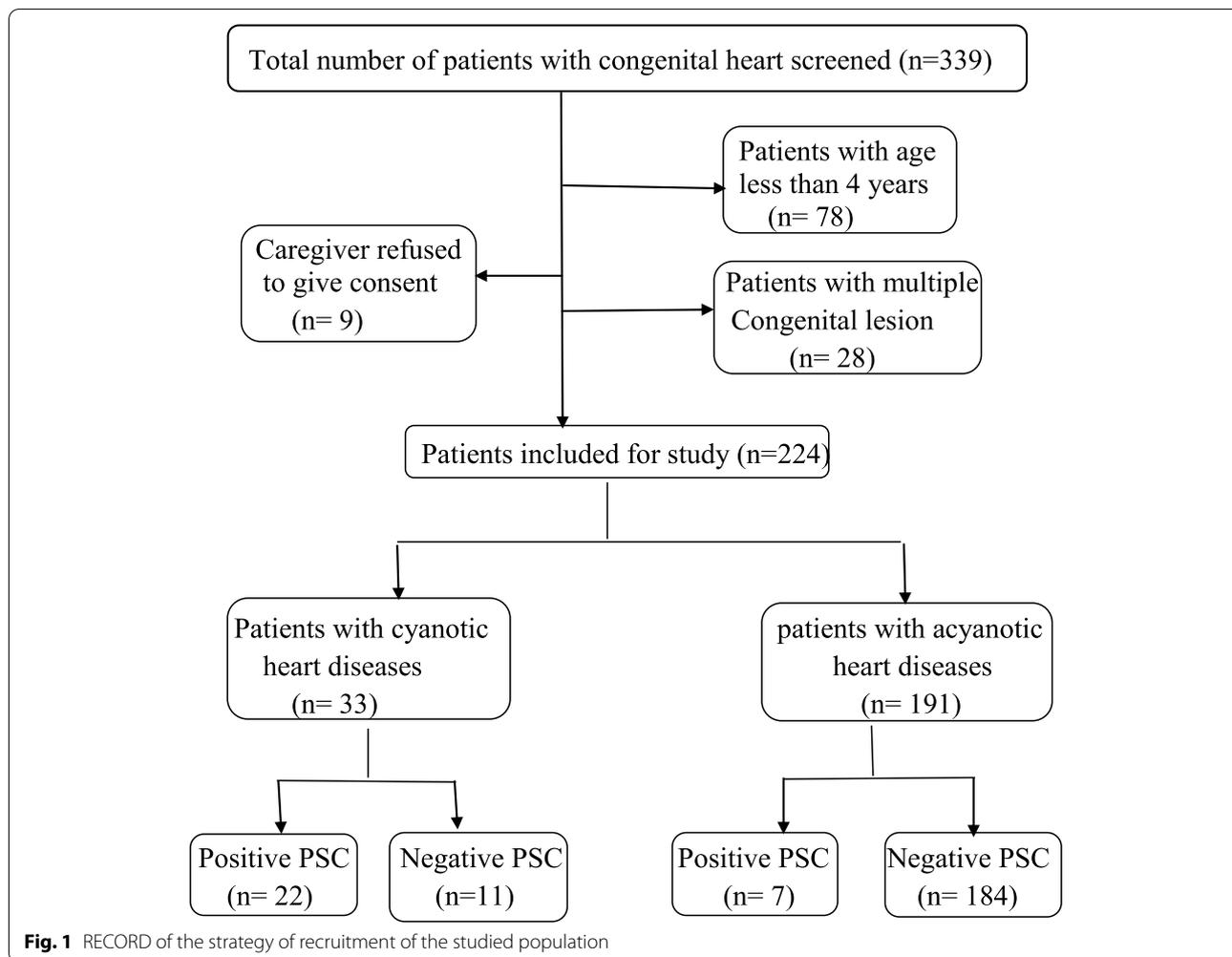
Statistical analysis used SPSS (Statistical Package for Social Science) program (version 21), where data was described using minimum, maximum, mean, standard deviation and 95% Confidence Interval (CI) of the mean, median and Inter-Quartile Range (IQR). Kolmogorov-Smirnov test of normality was carried for each variable. Comparisons were carried out between the studied groups using independent sample t test. Monte-carlo and Yate's (continuity) correction were carried out when indicated. Comparisons were carried out between two studied independent not-normally distributed subgroups using Mann-Whitney U test. The binary logistic model is used to estimate the probability of a binary response based on one or more predictor (or independent) variables. The calibration was assessed by directly comparing the observed and customized predicted positive internalizing defect across subcategories of risk. We employed the Hosmer–Lemeshow goodness-of-fit test, where a *p* value > 0.10 indicates acceptable calibration. Cronbach's (alpha) was used to estimate the reliability of the scores used in the study.

Ethical statement

All procedures performed in the current study were in accordance with the 1964 Helsinki Declaration and its amendments. The University ethical committee approved the study design on March 2018 (IRB:00007555-FWA:00018699, serial:0105443).

Results

The current study screened 339 patients visiting the out-patient clinic, Fig. 1 shows the Reporting of Studies Conducted using Observational Routinely-Collected health Data (RECORD) recruitment strategy. Table 1 shows the demographic and clinical data of the studied population (*n* = 224) with a median age of 86 months and inter-quartile range of (66–116 months). There were 54.46% (*n* = 122) male patients versus 45.54% (*n* = 102) female patients. The PSC screening revealed negative results concerning both attention and externalizing subscales and positive cases recorded to have internalizing problems only (12.95%, *n* = 29 patients) which are prone to develop depressive disorders. Table 2 shows that 10.27% (23 patients responded to the internalizing subscale positively, while 6.7% (15 patients) were retrieved as positive internalizing subscale due to their parents responses to



the PSC items. This means that 2.68% ($n=6$) patients responded negatively to the PSC score while their parents responded positively. 4% ($n=9$) patients and their parents confirmed having psychosocial defect, while 6.25% ($n=14$) patients reported having problems while their parents were not aware of their kids' sufferings).

Table 3 shows results of comparison between patients with positive total internalizing subscale of the PSC score compared to those with negative results. Significant risk factors were entered into a multiple logistic regression modeling shown in Table 4. Cyanosis was found to be the only significant independent risk factor for developing internalizing defects in the studied population ($p < 0.001$). Patients with cyanotic heart diseases were four folds at higher risk of developing internalization defects and depressive disorders compared to patients with acyanotic heart diseases.

Table 5 shows results of HR-QOL scores stratified into 4 domains: physical, emotional, social, and school functioning. Results revealed that the quality of school

functioning was the most affected domain with 4.46% ($n=10$) of patients being poor. While, the quality of social functioning was the least affected with 85.27% ($n=191$ patients) having excellent functioning capacities.

Table 6 shows the total Cronbach's alpha value of the PSC and HR-QOL scores among the studied population. Cronbach's alpha coefficient value of 0.846 reflects good reliability of the PSC score. While, Cronbach's alpha coefficient of 0.900 reflects excellent reliability of the HR-QOL score.

Discussion

Extensive research has documented neuro-developmental and psycho-social challenges among children and adolescents with CHD, prompting a scientific statement from the American Heart Association recommending periodic developmental surveillance, screening, evaluation, and re-evaluation [14]. The current study included 224 patients with CHD, aged 4–18 years with a mean \pm standard deviation of 99.48 ± 43.37 months. They

Table 1 Demographic data of the studied population

	n = 224	percent
Age at the study (months)		
Min-Max	48.00–223.00	100.00
Mean (Std. deviation)	99.48 (43.37)	
Median (IQR)	86.00 (66–116)	
Gender		
Male	122	54.46
Female	102	45.54
Cyanotic heart lesions^a		
	33	14.73
Fallot tetralogy	16	7.14
TGA	10	4.46
Ebstein anomaly	1	0.45
Double outlet right ventricle	4	1.79
Double inlet left ventricle	1	0.45
Tricuspid atresia	1	0.45
Acyanotic heart lesions		
	191	85.27
PS mild	3	1.34
moderate	2	0.89
severe	3	1.34
Bicuspid aortic valve	1	0.45
AS moderate	1	0.45
Severe	1	0.45
Coarctation of aorta	3	1.34
Subaortic membrane	18	8.04
VSD small	29	12.95
Large	63	28.13
ASD small	14	6.25
Large	41	18.30
MVP	19	8.48
PDA		
Tricuspid regurge mild	17	7.59
moderate	3	1.34
severe	2	.89
Dextrocardia	4	1.79
	4	1.79
Cyanosis	33	14.73
Controlled heart failure	44	19.6
Cardiac operation		
palliative operation	22	9.82
Corrective operation	98	43.75
Complication	1	0.45

TGA Transposition of great arteries PS pulmonary stenosis AS Aortic stenosis VSD: Ventricular septal defect ASD Atrial septal defect MVP mitral valve prolapse PDA Patent ductus arteriosus ^a: One patient may have more than one diagnosis

were 54.5% males ($n = 122$) and 45.5% females ($n = 102$). The PSC score implemented in this study revealed no cases with attention problems or externalizing defects. The only positive cases were found to have internalizing impairment (12.95%, $n = 29$). Interestingly, the PSC

Table 2 Results of Pediatric Symptom Checklist

	n	Percent
Total internalizing subscale results		
Negative	195	87.05
Positive	29	12.95
Total	224	100.00
Parents' internalizing subscale items		
Negative	209	93.30
Positive	15	6.70
Total	224	100.00
Patients' internalizing subscale items		
Negative	201	89.73
Positive	23	10.27
Total	224	100.00

Table 3 Comparison between patients with negative and positive results for the total internalizing subscale of PSC as regards variable risk factors

Risk factors	Internalizing subscale results		Test of significance (p value)
	Negative (n = 195)	Positive (n = 29)	
Age at study (months)			
Mean ± SD	100.73 ± 44.82	91.07 ± 31.33	$Z_{(MW)} = 0.628$
Median (IQR)	86 (66–116)	80 (65–102)	$p = 0.530$
Gender			
Male	107 (47.8%)	15 (6.69%)	$X^2_{(Y)}(df=1) = 0.014$
Female	88 (39.28%)	14 (6.25%)	$p_{(Y)} = 0.906$
Cardiac operation			
Not operated	93 (41.52%)	10 (4.46%)	
Palliative surgery	10 (4.46%)	12 (5.36%)	$X^2_{(df=3)} = 37.815$
Corrective surgery	91 (40.62%)	7 (3.125%)	$p_{(MC)} = 0.000^*$
complications	0 (0.0%)	1 (0.45%)	
Heart failure			
Negative	164 (73.2%)	16 (7.14%)	$X^2_{(Y)}(df=1) = 11.616$
Controlled	31 (13.84%)	13 (5.8%)	$p_{(Y)} = 0.001^*$
Cyanosis			
Negative	184 (82.1%)	7 (3.125%)	$X^2_{(Y)}(df=1) = 93.587$
Positive	11 (4.91%)	22 (9.82%)	$p_{(Y)} = 0.000^*$

SD Standard deviation IQR Interquartile range MW Mann-Whitney U test Y Yate (continuity) correction MC Monte Carlo test *: Statistically significant ($p < 0.05$)

items answered by the patients revealed only 23 patients with internalizing deficit. Considering the answers of parents' items in the PSC, 6 more patients were identified. The internalizing positive cases are more prone to develop anxiety or depressive disorders, positive cases were referred by the researcher to get psychological

Table 4 Multiple logistic regression of the significant risk factors for developing internalizing problems

Variables	B	Exp (B)	S.E	OR	95% CI		Sig
					Lower	Upper	
Constant	-3.557	0.029	0.618	33.142			
Palliative surgery	-1.006	0.366	0.979	1.057	0.054	2.489	0.304
Corrective surgery	0.356	1.430	0.771	0.215	0.315	6.481	0.643
Complication	-18.293	0.000	40,192.97	0.000	0.000	NA	1.000
Heart failure	0.647	1.910	0.690	0.879	0.494	7.386	0.348
Cyanosis	4.641	103.649	0.902	26.476	17.694	607.165	0.000*

OR Odds ratio CI Confidence interval NA not applicable due to low event rate *: statistically significant $p = 0.000$

The model was well calibrated (Hosmer – Lemeshow chi-square: 0.437, $p = 0.979$)

Table 5 Results of Quality of Life scoring assessment

Physical_functioning_problems	n	Percent
Fair (> 25–50%)	9	4.02
Good (> 50–75%)	27	12.05
Excellent (> 75–100%)	188	83.93
Total	224	100.00
Emotional functioning problems		
Fair (> 25–50%)	10	4.46
Good (> 50–75%)	76	33.93
Excellent (> 75–100%)	138	61.61
Total	224	100.00
Social functioning problems		
Fair (> 25–50%)	6	2.68
Good (> 50–75%)	27	12.05
Excellent (> 75–100%)	191	85.27
Total	224	100.00
School functioning problems		
Poor (0–25%)	10	4.46
Fair (> 25–50%)	22	9.82
Good (> 50–75%)	46	20.54
Excellent (> 75–100%)	146	65.18
Total	224	100.00

Table 6 Total Cronbach's alpha of Pediatric Symptom Checklist and Quality of Life scores

Scores	Item number	Cronbach's alpha	Cronbach's alpha on standardized items
PSC	35	0.846	0.829
QOL	23	0.900	0.893

PSC Pediatric Symptom Checklist QOL Quality Of Life

assessment and proper aid from a specialist. Consistent with the results of the present study, Latal et al [15] in their systematic review stated that psychological

difficulties consisted predominantly of internalizing symptoms as retrieved from six studies, while three studies only observed significant externalizing symptoms.

Assessment of possible risk factors related to positive PSC cases showed that surgical interference, heart failure with prolonged treatment, presence of cyanosis were identified statistically significant ($p < 0.001$, $p = 0.001$, $p < 0.001$ respectively). While age and gender were not statistically proven as risk factors ($p = 0.530$, $p = 0.906$ respectively). Cyanosis was found to be the only significant independent predictor of developing internalizing deficit by multiple logistic regression modeling ($p < 0.001$). Comparable to the current study, Areias et al. [16], stated that patients submitted to surgery had higher scores in PSC, namely internalization subscale ($p = 0.007$), externalization subscale ($p = 0.024$), and attitude subscale ($p = 0.011$). Moreover, relatives of their patients referred more to internalization defects ($p = 0.006$) for the complex forms of CHD and those having physical limitations ($p = 0.027$). Special emphasis on cyanosis was observed by Latal et al [15] in their systematic review; they found that rates of psychiatric disorders for children with surgically corrected transposition of great arteries and children with severe cyanotic defects ranged between 19 and 46%. In line with these findings, parents of children with cyanosis or reduced physical capacity reported psychological maladjustment especially following surgery as reported by Gupta et al [17] and Bjornstad et al. [18]

Identification of the child with significantly impaired QOL may have the greatest clinical potential for improving outcomes of children with heart disease. Results of HR-QOL score in the current study showed that the majority of studied patients had excellent quality of life as regards the four domains: physical, emotional, social, and school functioning (83.93%, 61.61%, 85.27%, and 65.18% respectively). The worse physical functioning reported was fair in 4.02% ($n = 9$), the worse emotional functioning

was fair in 4.46% ($n=10$), social functioning was fair in 2.68% ($n=6$). The domain most affected was the school performance being poor in 4.46% ($n=10$), and fair in 9.82% ($n=22$) of the studied patients. These results are in accordance with many other researches in literature. Krol et al [19] stated that although significantly lower than the scores of healthy children on several domains, yet mean health-related quality of life scores of children with CHD remained relatively good. Moons et al [9] stated that 78.1% were clustered as having a good QOL, 20.1% had moderate QOL, and only 1.8% ($n=11$) had poor QOL within a study of 612 adults with CHD. Many studies confirmed the poorer psychological well-being and QOL in CHD patients compared to healthy controls [20, 21]. Uzark et al [22] concluded that comparison of the mean subscale scores for physical, emotional, social, and school QOL revealed that children with CHD were most different than norms especially school functioning scores ($p<0.001$). Even though, they added that the majority of these children had a good QOL as perceived by themselves and their parents. The strong religious believes together with the familial consolidation in the setting of the current study helped children and their families to accept and better deal with their suffering as they conceived the disease as “the will of God”. This statement was recorded repeatedly by many families while performing the study. This explains why despite of the low to moderate socio-economic class of the studied population, yet the prevalence of psycho-social impairment and hence the quality of life were found comparable to that recorded in well - developed centers.

The results of the present study showed that measures of internal consistency were high for the two metrics used in the study. The total Cronbach's alpha of PSC ($\alpha=0.846$) which refers to it as a good tool of psychosocial assessment among the studied population. While, the total Cronbach's alpha for the HR-QOL was estimated to be ($\alpha=0.900$) and this refers to an excellent tool of assessment of quality of life among the studied cases. The PSC have been widely used for research and have demonstrated sound psychometric properties. In a huge study by Gardner et al [4] that involved 18,045 patients within a primary care setting, PSC demonstrated good overall internal consistency ($\alpha=0.89$) very comparable to the results of the current study. The PSC was also found to have good sensitivity and specificity when compared to similar well validated measures [23]. The HR-QOL tool developed by WHO is more widely valid and reliable psychometric analysis with excellent internal consistency in the study by DeSmedt et al. [24], Cronbach α was found to be 0.92, again very close to the current results. This was proved to be a better tool of analysis if compared to a specific cardiac disease related QOL score developed by

Leiden University Medical Centre which reported a questionable reliability. ($\alpha=0.63$) [19].

The PSC and HR-QOL scores proved to be effective and valuable instruments for the evaluation of patients with CHD given the increasing number of survivors. Recommendation from previous results suggests to combine both scores for screening children with psycho-social deficit and further detect those with poor quality of life. Applying one tool of screening would probably be less effective in detecting CHD patients in need for psychological support. This goes in parallel with Struempel et al [25] who concluded that PSC as a psychosocial screening tool could not detect impairments in executive, behavioral, social, cognitive and emotional adjustment. These domains are well covered by WHO – HR/QOL tool. So, the combined use of PSC and HR-QOL tools provides better insight into knowledge gaps or unrecognized psychosocial needs.

This study was not without limitations. First, although the size of the studied cases was large enough to produce sufficient power analysis, larger groups could contribute to generalizability of study results. Second, a multi-center collaboration is a means of increasing the number of participants and further expanding knowledge and understanding of the emotional and psychosocial aspect of heart diseases. The third weakness of the study is the potential sample bias because studied patients were recruited from cardiology outpatient clinic and this cohort could not represent the whole CHD population. It is unknown whether patients not receiving specialized care have better or poorer psycho-social functioning. Finally, patient functional status was quantified by subjective rather than objective assessment in view of the age of the studied group whether too young to understand and decide scores, or adolescent age which is basically a time of intense psychological changes and instability even among healthy individuals. So, results of these scores should be interpreted with lot of caution of misleading.

Conclusions

This study bears important implications for implementing psychosocial screening tools as a routine work-up within the cardiology out-patient clinic. This systematic screening could result in increased identification of patient in need for psychology specialist help in order to help them improve their quality of life.

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Authors' contributions

Aly Abdel-Mohsen was responsible for data analysis and revision of the manuscript. Mona Gamal Kassem - was responsible for protocol development, data collection. Manal A-M Antonios was responsible for the idea of the research, protocol development, data analysis and writing of the manuscript. The

corresponding author has full access to data and has the right to publish such data. The author(s) read and approved the final manuscript.

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Availability of data and materials

All raw data and materials are available upon request from the corresponding author via an email.

Declarations

Ethics approval and consent to participate

All procedures performed in the current study were in accordance with the 1964 Helsinki Declaration and its amendments. The University ethical committee approved the study design on March 2018 (IRB:00007555-FWA:00018699, serial:0105443). After explaining the benefit of the study to parents or caregivers of the patients, a consent to participate in the study was obtained.

Consent for publication

An informed written consent was obtained for the purpose of publication.

Competing interests

All authors of this article declare no conflict of interest.

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