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Original Article

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Abstract

Objectives: The diagnosis of CHD not only affects the patient but also their entire environment, including parents, causing significant alterations in their mental health. This study was to assess the levels of anxiety and depression in parents of children with CHD at different stages of the disease. **Methods:** The PMNCC and PMNCR questionnaires were administered to parents of children with CHD to measure levels of state anxiety (STAI-E) and trait anxiety (STAI-R). **Results:** A total of 459 questionnaires were administered. For the state anxiety questionnaire (STAI-E), the mean score was 36, with high anxiety levels observed in 81.3% of participants and above-average levels in 18.7%. Regarding the severity of state anxiety, 82.6% presented severe anxiety, followed by moderate anxiety in 17.2%. For the trait anxiety questionnaire (STAI-R), the mean score was 43, with high levels observed in 91.5% of participants and above-average levels in 7.2%. Severe anxiety predominated in 96.7% of cases. **Conclusions:** The mental health of parents of children with CHD is often neither diagnosed nor adequately addressed in a timely manner by paediatric cardiology teams. Assessment and support from a multidisciplinary team are required for the early identification of these conditions.

Introduction

CHDs are the most common congenital defects at birth,¹ with a worldwide prevalence of 8 per 1000 live births.² Advances in paediatric cardiology, including imaging techniques, cardiac surgery, and both diagnostic and therapeutic interventional procedures, have allowed more than 85% of these patients to survive into adulthood.³ Currently, the main approach not only in paediatric cardiology but also in general medicine is multidisciplinary care. In recent years, special emphasis has been placed on psychological care, as it has been observed that both patients and their families experience significant socio-legal and emotional disturbances.³

Multiple studies have focused on identifying psychological alterations in children with CHD; however, very few have investigated psychosocial morbidity among parents, who may develop multiple psychological disturbances in the short and medium term. Critical events include diagnosis, prolonged hospital stays, invasive procedures, and subsequent interventions, all of which may lead to psychological problems.¹ In the study conducted by Lawoko et al.,⁴ it was found that patients with CHD may present persistent psychological problems in 7–22% of cases, mainly depression (18%), anxiety (16–18%), somatisation (31–38%), and hopelessness (16%). Similarly, the systematic review conducted by Woolf-King et al.⁵ showed that approximately 25–50% of parents of children with CHD present elevated symptoms of depression and/or anxiety. In addition, these high levels of parental stress and intense emotions can affect parental behaviour, disrupt the parent–child relationship by reducing parental sensitivity, and negatively impact the well-being of both the child and the parent.⁶

In many cases, these disorders are not only related to the patient's underlying condition but are also compounded by social and economic factors, which are often limited and require additional support that is not provided in many institutions. Therefore, the objective of this study was to identify psychological alterations in parents of children with CHD at different stages of care, from diagnosis to resolution, among patients treated at our institution.

Methods

A cohort study was conducted, including the stress and anxiety levels experienced by parents of children with congenital heart disease (PMNCC) and stress and anxiety levels experienced by parents of children with congenital heart disease who do not undergo surgery (PMNCR)

Table 1. Interpretation of PMNCC and PMNCR

Category	A/E (state anxiety)	Category	A/R (feature anxiety)
High	32–63	Normal or no anxiety	0–9
Above average	23–31	Mild or moderate	10–18
Average	20–22	Moderate to severe	19–29
Average tendency	15–19	Severe	30–63
Low	0–14	–	–

questionnaires. The quantitative component involved comparing scores from two questionnaires that measure state anxiety (STAI-E) and trait anxiety (STAI-R). These were administered to parents during paediatric cardiology outpatient visits, including parents of patients undergoing surgical protocols as well as those who had already undergone surgical or interventional procedures. Patients with both univentricular and biventricular physiology were included.

Questionnaire scores ranged from 0 to 63. The following guidelines are recommended for interpretation (Table 1).

Statistical analysis

A descriptive analysis was performed by estimating minimum and maximum values and percentages for continuous numerical variables, and percentages for categorical variables. Inferential statistics included the chi-square test for qualitative variables and the *t* test for quantitative variables, with a significance cut-off of 0.005.

Results

Demographic characteristics

A total of 459 questionnaires were administered in the paediatric cardiology outpatient clinic to guardians or parents of children with CHD.

The predominant patient sex was male (52.9%). The mean age was 5 years, with patients ranging from the neonatal period to 14 years of age. The main age group was children older than 6 years (41.8%), followed by those aged 6 months to 2 years (31.8%). A genetic syndrome was present in 26.6% of cases.

Regarding the type of heart disease, biventricular physiology predominated (87.1%) and 62.7% of cases were acyanotic. Previous surgery was reported in 48.6% of patients, of which 50.5% were corrective procedures.

With respect to the therapeutic plan, 26.4% of patients were undergoing a surgical protocol, while 12.2% were not receiving surgical management (Table 2).

In 93.2% of cases, the questionnaires were completed by mothers. The demographic characteristics of respondents are shown in Table 3.

Questionnaire results

For the state anxiety questionnaire (STAI-E), the mean score was 36. High anxiety levels were observed in 81.3% of participants, while 18.7% showed above-average levels. Regarding severity, 82.6% presented severe anxiety and 17.2% moderate anxiety.

Table 2. Demographic and clinical characteristics of patients with CHD

Variable	<i>n</i> = 459
Gender	Male <i>n</i> = 243 (52.9%) Female <i>n</i> = 216 (47.1%)
Age	0–168 months (67 months) Age group: <6 months: <i>n</i> = 34 (7.4%) 6 months–2 years: <i>n</i> = 146 (31.8%) 3–6 years: <i>n</i> = 87 (19%) >6 years: <i>n</i> = 192 (41.8%)
Heart disease	Physiology Univentricular: <i>n</i> = 59 (12.9%) Biventricular: <i>n</i> = 400 (87.1%) Guy : Cianogena: <i>n</i> = 171 (37.3%) Acianogena: <i>n</i> = 288 (62.7%)
Procedure performed	Catheterisation: <i>n</i> = 81 (17.6%) Surgery corrective: <i>n</i> = 232 (50.5%) Palliative surgery: <i>N</i> = 59 (12.9%)
Management plan	Surveillance: <i>n</i> = 101 (22%) Surgical: <i>n</i> = 181 (39.4%) Surgical protocol: <i>n</i> = 121 (26.4%) Not operable: 56 (12.2%)
Genetic syndrome	<i>n</i> = 122 (26.6%)

Table 3. Demographic characteristics of respondents

Variable	<i>n</i> = 459
Parent taking the survey:	<i>n</i> = 428 (93.2%)
Mother	<i>n</i> = 31 (6.75%)
Father	
Age:	<i>n</i> = 121 (26.3%)
<20 years	<i>n</i> = 233 (50.7%)
21–40 years	<i>n</i> = 105 (22.8%)
41–60 years	
Education:	<i>n</i> = 192 (41.8%)
Primary	<i>n</i> = 145 (31.5%)
Secondary	<i>n</i> = 89 (19.3%)
High school	<i>n</i> = 33 (7.1%)
Degree	
Employment status	<i>n</i> = 168 (36.6%)
Employed	<i>n</i> = 291 (63.3%)
Unemployed	

For the trait anxiety questionnaire (STAI-R), the mean score was 43, with high levels observed in 91.5% of participants and above-average levels in 7.2%. Severe anxiety predominated in 96.7% of cases (Table 4).

STAI-E (state anxiety) questionnaires

No significant associations were observed between the patient's age group and high or above-average state anxiety levels, as patients older than 6 years predominated in both categories (38.3% and 60.5%, respectively). No significant association was found between anxiety level and cardiac physiology, with biventricular physiology predominating in both high anxiety (84.7%) and above-average anxiety (97.7%). However, this may be explained by the higher proportion of patients with biventricular physiology in the sample.

Table 4. Questionnaire results

Questionnaire	Score	Outcome	Type
A/E outcome (state)	23–58 (Mean 36)	High <i>n</i> = 420 (91.5%) Above average <i>n</i> = 33 (7.2%) Average <i>n</i> = 3 (0.7%) Average tendency <i>n</i> = 3 (0.7%)	Mild <i>n</i> = 1 (0.2%) Moderate <i>n</i> = 79 (17.2%) Severe 379 (82.6%)
A/R outcome (feature)	22–57 (Mean 43)	High <i>n</i> = 420 (91.5%) Above average <i>n</i> = 33 (7.2%) Average <i>n</i> = 3 (0.7%) Average tendency <i>n</i> = 3 (0.7%)	Moderate <i>n</i> = 15 (3.3%) Severe <i>n</i> = 444 (96.7%)

Associations.

A/E State.

Table 5. Associations of A/E state outcome with variables

Variable	High	Above average	IC, <i>p</i> value
Age:	31 (8.3%)	3 (3.5%)	<i>p</i> : 0.01
<6 months	133 (35.7%)	13 (15.1%)	IC 0.11–0.12.
6 months–2 years	69 (18.5%)	18 (20.9%)	
3–6 years	140 (38.3%)	52 (60.5%)	
>6 years			
Physiology	57 (15.3%)	2 (2.3%)	<i>p</i> : 0.01
Univentricular	316 (84.7%)	84 (97.7%)	IC 0.000–0.001
Biventricular			
Type of heart disease	150 (40.2%)	223 (59.8%)	<i>p</i> : 0.005
Cyanogenic	21 (24.4%)	65 (75.6%)	IC 0.004–0.006
A cyanotic			
Plan:	55 (14.7%)	46 (53.6%)	<i>p</i> : 0.02
Surveillance	141 (37.8%)	40 (46.5%)	IC: 0.000–0.001
Surgery	121 (32.4%)		
Surgical protocol	56 (15%)		
Inoperable			
Type of surgery	166 (44.5%)	20 (23.3%)	<i>p</i> : 0.01
Corrective	59 (15.8%)		IC: 0.005–0.008
Palliative			
Genetic syndrome	98 (26.3%)	24 (77.9%)	<i>p</i> : 0.4 IC 0.22–0.34

A/R Feature.

A significant association was observed in patients with cyanotic CHD, with high anxiety levels present in 40.2% of cases. Additionally, parents of patients who had already undergone corrective procedures presented elevated anxiety levels (Table 5).

STAI-R (trait anxiety) questionnaire

The main trait anxiety categories were moderate and severe; however, these groups were not comparable, as only 3.2% of the total sample presented moderate trait anxiety, while the remainder presented severe anxiety. No significant differences were found among age groups, with moderate anxiety observed in 60% and severe anxiety in 42.5%.

Regarding cardiac physiology, biventricular physiology predominated, accounting for 100% of moderate cases and 86.7% of severe cases. With respect to the type of CHD, cyanotic heart disease predominated in severe trait anxiety, with a statistically significant *p* value of 0.002. Parents of patients who had already

Table 6. Associations of A/R trait outcomes with variables

Variable	Moderate	Severe	IC, <i>p</i> value
Age:	0	34 (7.7%)	<i>p</i> : 0.094
<6 months	3 (20%)	143 (32.2%)	IC :0.59–0.61
6 month–2 years	9 (60%)	78 (17.6%)	
3–6 years	3 (20%)	189 (42.5%)	
>6 years			
Physiology	0	59 (13.3%)	<i>p</i> : 0.13
Univentricular	15 (100%)	385 (86.7%)	IC 0.22–0.23
Biventricular			
Type of heart disease	0	15 (100%)	<i>p</i> : 0.002
Cyanotic	171 (38.5%)	385 (86.7%)	IC 0.22–0.23
A cyanotic			
Plan:	15 (100%)	86 (19.4%)	<i>p</i> : 0.00
Surveillance		181 (40.8%)	IC: 0.0–0.2
Surgery		121 (27.3%)	
Surgical protocol		56 (12.2%)	
Inoperable			
Type of surgery	9	223	<i>p</i> : 0.35
Corrective	0	59	IC: 0.25–0.27
Palliative			
Genetic syndrome	0	122	<i>p</i> : 0.05 IC 0.036–0.04

undergone surgery also predominated in the severe trait anxiety group, accounting for 40.8% of cases (Table 6).

Discussion

When a child is diagnosed with CHD, a medical–surgical care plan is initiated, posing multiple challenges for parents. These include frequent medical appointments, numerous diagnostic and therapeutic procedures, prolonged hospitalisations, multiple surgeries, and exposure to life-threatening situations.⁹ Parents and families may experience psychological and social sequelae associated with the diagnosis, acceptance of the disease, illness perception, and the demands of raising a child with CHD. Social stereotypes may influence coping behaviours in both parents and children, exacerbating social isolation and marginalisation.^{9,10}

The economic dimension must also be considered, as parents often experience financial instability due to work absences and increased medical expenses, negatively affecting their overall health. Consequently, the burden of care falls directly on parents, who endure sustained pressure throughout the course of their child's illness.¹¹ Therefore, caregiver involvement and well-being

must be considered a priority, as parental mental health directly impacts both their own quality of life and their child's treatment outcomes.¹²

Several instruments are available to assess anxiety levels, among which the STAI is one of the most widely used. It measures two dimensions: state anxiety, a transient emotional condition characterised by tension and apprehension, and trait anxiety, a relatively stable predisposition to perceive situations as threatening.⁷

In this study, parents who reported high and statistically significant levels of state anxiety were predominantly those whose children had cyanotic CHD (40.2%). The remaining variables did not show statistical significance, consistent with the findings reported by Hoyos et al.⁸

Regarding the therapeutic stage, Hoyos et al.⁸ reported anxiety symptoms in 29.2% of parents during the preoperative period, similar to our findings (27.3% with severe anxiety), increasing to 40.8% among parents of patients who had already undergone surgery.

Conclusions

The results indicate that parents of children with CHD are at significant risk of developing psychological disorders, particularly anxiety. In many cases, emotional and social support is insufficient. Therefore, healthcare teams should incorporate specific interventions focused on education, coping strategies, and psychological and social support as part of comprehensive multidisciplinary care.

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Author contribution. All authors contributed to the study conception and design.

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