



## Original Article



## Association Between Social Support and Psychological Distress of Parents Having Children with Congenital Heart Disease

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## ARTICLE INFO

**Keywords:**

Congenital Heart Disease, Social Support, Psychological Distress, Care

**How to Cite:**Ullah, H., Ali, S., Muhammed, D., Ali, H., Arshad, S., Hussain, S., & Daulat, I. (2025). Association Between Social Support and Psychological Distress of Parents Having Children with Congenital Heart Disease: Psychological Distress of Parents Having Children with Congenital Heart Disease. *NURSEARCHER (Journal of Nursing & Midwifery Sciences)*, 5(3), 51-56. <https://doi.org/10.54393/nrs.v5i3.196>**\*Corresponding Author:**

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sardar.ins@kmu.edu.pkReceived Date: 15<sup>th</sup> July, 2025Revised Date: 19<sup>th</sup> September, 2025Acceptance Date: 23<sup>rd</sup> September, 2025Published Date: 30<sup>th</sup> September, 2025

## ABSTRACT

Congenital heart diseases are prevailing around the globe in terms of their morbidity and mortality, which need special attention to address them appropriately. Congenital Heart Diseases not only affect the affected children but it drastically traumatizes their parents as well.

**Objectives:** To determine the association between social support and psychological distress among parents having children with congenital heart disease in Peshawar. **Methods:** This analytical cross-sectional conducted at the Peshawar Institute of Cardiology over span of six-month period using convenience sampling; data were collected at one time without changing factors. Families with children were the sole focus. SPSS version 22.0 was utilised for data analysis after the DASS-13 and MSPSS questionnaires were used to collect the data. **Results:** The survey identified significant ( $p < 0.050$ ) predictors of psychological distress. Joint families had lower anxiety ( $14.9 \pm 6.6$  vs  $11.0 \pm 7.2$ ,  $p < 0.001$ ) and depression scores ( $15.8 \pm 8.3$  vs  $13.1 \pm 7.4$ ,  $p = 0.002$ ). A strong, statistically significant association was found between higher levels of social support and lower severity of depression (Fisher's Exact Test,  $p < 0.001$ ). Across all three psychological distress indicators. No significant gender differences in distress levels were observed. Parents in nuclear families reported significantly higher anxiety ( $14.9 \pm 6.6$ ) and depression ( $15.8 \pm 8.3$ ) compared to those in joint families (anxiety:  $11.0 \pm 7.2$ ,  $p < 0.001$ ; depression:  $13.1 \pm 7.4$ ,  $p = 0.002$ ). **Conclusions:** This study underlines how crucial social support is for mental health, in addition to age, education, and familial relationships.

## INTRODUCTION

Congenital Heart Disease (CHD) refers to structural or functional abnormalities of the heart that are present at birth and interfere with normal cardiac physiology. It is classified into cyanotic CHD, where oxygen-poor blood enters systemic circulation, and a cyanotic CHD, where oxygenated blood is abnormally shunted but cyanosis is absent [1]. Psychological distress refers to emotional distress that is typified by stress, anxiety, and depression symptoms [2]. Income, education, and occupation are among the socioeconomic factors that shape access to

healthcare and coping mechanisms. Social support refers to emotional, instrumental, and informational support given to individuals by family members, friends, and the community to reduce the burden of illness [3]. These aspects, psychological suffering, socioeconomic status, and social support, are inextricably linked to the family of CHD children. Emotional distress may be worsened by financial strain, low education, and caregiving responsibilities, and buffered by an adequate social structure of family, friends, and community and improve



coping. The method of interaction is fundamental to assessing the outcomes of the mental health of parents and developing specific interventions. CHD is one of the most prevalent congenital abnormalities globally, with a prevalence of 9 to 10 out of 1000 live births. The prevalence of the disease is 8 to 12 cases per 1,000 live births in the Asian countries, and it is estimated to be between 10 and 15 cases per 1,000 live births in South Asia [4]. In Pakistan, CHD has been estimated to have 10-12 cases out of 1,000 live births, but due to underdiagnoses in rural and underserved areas there could be more cases than that. Peshawar Institute of Cardiology (PIC) is one of the facilities that offer specialized treatment, although due to limited resources and large patient numbers, the burden falls to families and healthcare systems [5, 6]. CHD is a significant cause of infant morbidity and mortality. Severe defects like Tetralogy of Fallot (TOF) and Transposition of the Great Arteries (TGA) require complex surgeries, while milder conditions such as atrial septal defect (ASD) and ventricular septal defect (VSD) may need less intervention [7]. Survival rates have improved through prenatal screening and surgical advancements, yet many patients face long-term complications, including arrhythmias, heart failure, and recurrent hospitalizations. Families must adapt to lifelong care needs, creating a sustained physical, emotional, and financial burden [8, 9]. Parents of children with CHD frequently experience heightened psychological distress due to constant uncertainty, repeated hospitalizations, and the threat of life-threatening emergencies. Anxiety and depression are common, particularly among mothers who carry the primary caregiving role [10, 11]. Financial challenges and caregiving responsibilities interfere with parents' daily living, professional commitments, and social relationships. Studies in Pakistan have shown that over half of parents of CHD children report significant dysphoria that limits social and occupational functioning [12]. Low income and poor education exacerbate the challenges of managing CHD. In Pakistan, where healthcare is costly and insurance coverage is limited, families rely on out-of-pocket payments, loans, or selling property to finance surgeries and treatments. Geographic barriers in Khyber Pakhtunkhwa (KPK) further restrict access, forcing families to travel long distances to urban centers like Peshawar. Limited parental literacy, particularly among women, restricts comprehension of medical advice and hinders timely health-seeking behavior [13, 14]. Social support is an important determinant of parental psychological well-being. Emotional support provides reassurance and reduces isolation, instrumental support helps in managing financial and practical needs, while informational support empowers parents to make informed decisions [12]. In South Asian cultures, extended families often share caregiving responsibilities, providing

both emotional and financial help. However, the availability of such support is inconsistent, and in some cases, cultural norms increase pressure on mothers, who may face blame for the child's condition [13]. While congenital heart disease (CHD) is recognized globally as a leading cause of morbidity and mortality in children, evidence on the psychological impact on parents in Pakistan remains limited. Most existing studies focus on clinical outcomes or are conducted in high-income countries, which may not reflect the sociocultural and healthcare realities of Pakistani families.

Although congenital heart disease (CHD) is a major cause of childhood morbidity and mortality, limited research in Pakistan has explored the psychological impact on parents, particularly in relation to social support. Most existing studies focus on clinical outcomes or are conducted in high-income countries, leaving sociocultural factors and local caregiving challenges underexamined. Understanding these dynamics is essential to identify vulnerable families and guide context-specific interventions. This study aims to explore the association between perceived social support and psychological distress among parents of children with CHD in Pakistan.

## METHODS

The present study used an analytical cross-sectional design to examine the association of psychological distress and perceived social support in parents of children with congenital heart disease (CHD). This is the type of design that is most suitable for determining associations and correlational relationships amongst variables that do not involve long-term follow-up and experimental control. The research was done in the Peshawar Institute of Cardiology (PIC), a tertiary care facility in Khyber Pakhtunkhwa, Pakistan, offering diagnostic, operating, and follow-up services to children with congenital heart issues. The research was carried out from September 2024 to January 2025, which included planning, recruitment, data collection, and analysis. Informed written consent of all the participants was obtained after receiving ethical approvals of the Institutional Review Board (IRB) of Khyber Medical University with ref no: IRC/24/92, PIC administration, and other regulatory authorities. Data collection was done by the principal investigator himself to ensure consistency and the confidentiality of the participants. Face-to-face structured interviews in an intimate environment were used to gather data in the pediatric cardiology outpatient clinic so as to achieve privacy and comfort. Sessions were approximately 20 minutes long, and the participants had been briefed on the objectives of the study and confidentiality. The investigator was present to clarify queries and ensure accurate responses. The study population comprised parents of children aged 1-10 years who were diagnosed

with congenital heart disease, including ventricular septal defect (VSD), atrial septal defect (ASD), and patent ductus arteriosus (PDA). Parents with acquired heart conditions in their children, or those with pre-existing anxiety or depression, were excluded. Using Raosoft's sample size calculator with a 95% confidence interval, 5% margin of error, and a population size of 3000, the estimated sample size was 341 participants. This yielded a minimum required sample size of 341 participants. Stating a 50% response distribution ensures maximum variability and produces the most conservative (largest) sample estimate, enhancing representativeness. A convenience sampling technique was applied, recruiting parents who visited the PIC outpatient department for follow-ups or consultations. Data were collected through a structured questionnaire with three sections: (1) demographic details, (2) the Urdu-validated Depression, Anxiety, and Stress Scale-21 (DASS-21), and (3) the Urdu-validated Multidimensional Scale of Perceived Social Support (MSPSS). Both tools demonstrated strong psychometric reliability and cultural relevance in prior studies conducted in Pakistan. All analyses were performed using SPSS version 22.0. Before applying the Pearson Chi-square test, assumptions of expected cell counts (>5 in at least 80% of cells) were verified to ensure statistical validity. In cases where assumptions were borderline, Fisher's Exact Test was applied as an alternative for categorical comparisons. Additionally, correlation analyses were performed to assess the strength and direction of associations between perceived social support and continuous psychological distress scores. A p-value of <0.050 was considered statistically significant.

**RESULTS**

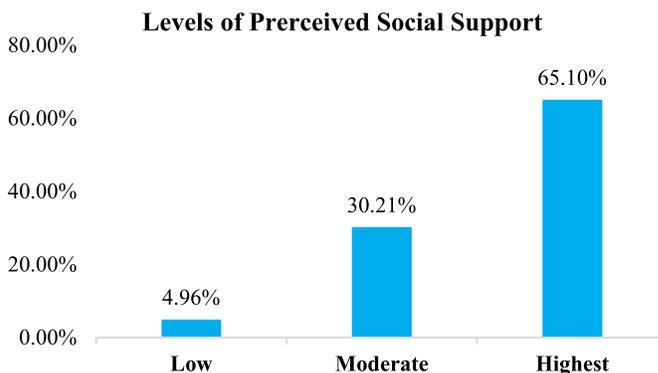
The demographic findings show that most parents were aged 31-40 years (40.5%), with nearly equal representation of males (50.4%) and females (49.6%). An independent samples t-test revealed no statistically significant differences in depression, anxiety, or stress scores between male and female participants (p>0.050 for all comparisons, indicating that psychological distress levels were similar across genders. Education levels varied, with 37% having primary to secondary education, while 32% were illiterate. More than half of the respondents (56.3%) lived in nuclear families, and 43.7% belonged to joint families. These characteristics highlight a diverse parental background relevant to understanding their psychological and social support needs (Table 1).

**Table 1:** Demographic Characteristics of Participants (n=341)

Variables	Category	n (%)
Age (Years)	20-30	103 (30.2%)
	31-40	138 (40.5%)
	41-50	100 (29.3%)

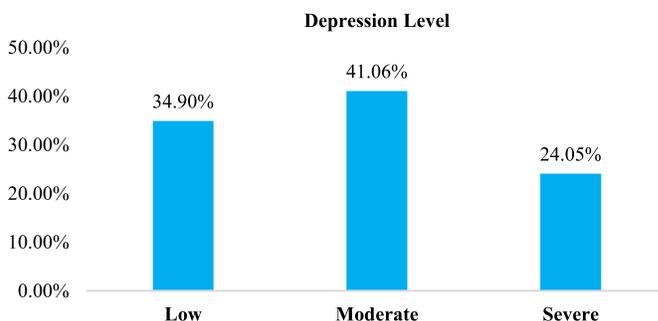
Gender	Male	172 (50.4%)
	Female	169 (49.6%)
Education Level	Illiterate	109 (32.0%)
	Primary-Secondary	126 (37.0%)
	Higher Secondary+	106 (31.0%)
Family Structure	Nuclear	192 (56.3%)
	Joint	149 (43.7%)

This bar chart illustrates the distribution of perceived social support levels among 341 participants, as measured by the MSPSS. The results are categorized into three distinct levels: low (12-36), moderate (37-60), and highest (61-84) support. The visualization clearly highlights that the majority of participants (65.10%) reported experiencing the highest level of perceived social support, represented by the tallest bar. A significant portion (30.21%) fell into the moderate support range, shown by the middle bar, while only a small minority (4.69%) indicated low support, depicted by the shortest bar (Figure 1).



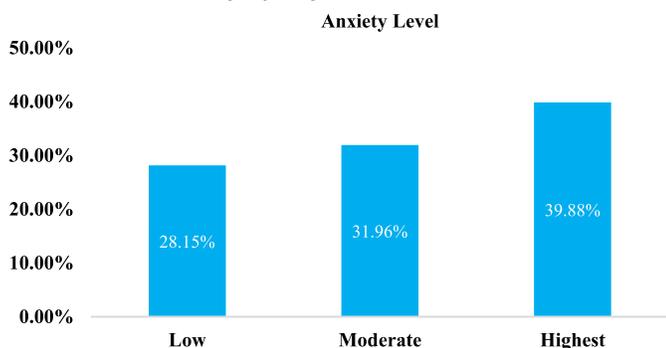
**Figure 1:** Percentage Distribution of MSPSS Social Support Categories

The DASS-21 depression scores show that most participants (140) report moderate depression. A comparatively smaller portion (119 participants) reports mild depression, and the smallest group (82 participants) reports severe depression. The box plot representing depression scores will illustrate the distribution across mild, moderate, and severe depression categories, highlighting the greater spread of scores in the mild and moderate categories compared to the severe category (Figure 2).



**Figure 2:** DASS-21 Depression Score Distribution

Anxiety scores, as measured by the DASS-21, out of the total participants, 96 report mild anxiety, another 109 report moderate anxiety, and 136 report severe anxiety. The box plot for anxiety scores will show the distribution of scores in each category (Figure 3).



**Figure 3:** DASS-21 Anxiety Score Distribution

Three age categories were examined for variations in psychological distress: Category I (18–28 years; n = 107), Category II (29–38 years; n = 165), and Category III (39–55 years; n = 69). One-way analysis of variance revealed statistically significant differences between age groups for stress, depression, and anxiety ( $p < 0.001$  for all). Post-hoc analysis using the Games-Howell test indicated that the youngest parents (Category I, 18–28 years) reported significantly higher levels of stress, depression, and anxiety compared to both older age groups (Categories II and III). The differences between Category II and Category III were not statistically significant for any of the distress measures. These results indicate that younger age is associated with higher psychological distress in this population (Table 2).

**Table 2:** Age Group Differences in Psychological Distress Measures

Variables Categories	Age Category I (18-28)	Age Category II (29-38)	Age Category III (39-55)	Statistical Test	Effect Size
Stress	19.07 ± 3.84	16.23 ± 6.57	13.57 ± 7.05	F=18.39, p<0.001	$\eta^2=0.098$
Depression	16.77 ± 6.29	14.58 ± 8.81	10.81 ± 7.06	F=12.39, p<.001	$\eta^2=0.068$
Anxiety	15.27 ± 5.89	12.52 ± 7.47	11.04 ± 7.35	F=8.71, p<.001	$\eta^2=0.049$

Across all three psychological distress indicators—depression, anxiety, and stress—Fisher's Exact Tests demonstrated statistically significant associations with social support. The Pearson Chi-Square tests demonstrated statistically significant associations with social support. All p-values were below 0.050, confirming the rejection of the null hypothesis and the acceptance of the alternative hypothesis that social support significantly influences psychological well-being. The data consistently show a negative relationship between social support and psychological distress. Parents who receive high levels of

support are substantially less likely to experience severe depression, anxiety, or stress, while those with minimal support are more vulnerable to these conditions. These findings highlight the protective role of social support in coping with the psychological challenges of raising a child with a serious health condition such as congenital heart disease. Interventions aimed at enhancing social support structures could therefore play a critical role in improving mental health outcomes for these parents (Table 3).

**Table 3:** Association Between Social Support and Psychological Distress Severity

Psychological Distress Measure	Social Support Level	Distress Severity, n (%)				p-Value
		Mild	Moderate	Severe	Total (n)	
Depression	Low	0 (0.0%)	42 (35.3%)	77 (64.7%)	119	<0.001*
	Moderate	0 (0.0%)	29 (20.7%)	111 (79.3%)	140	
	High	16 (19.5%)	32 (39.0%)	34 (41.5%)	82	
Anxiety	Low	0 (0.0%)	23 (24.0%)	73 (76.0%)	96	0.012*
	Moderate	9 (8.3%)	38 (34.9%)	62 (56.9%)	109	
	High	7 (5.1%)	42 (30.9%)	87 (64.0%)	136	
Stress	Low	0 (0.0%)	66 (32.0%)	140 (68.0%)	206	<0.001*
	Moderate	16 (14.0%)	23 (20.2%)	75 (65.8%)	114	
	High	0 (0.0%)	14 (66.7%)	7 (33.3%)	21	

## DISCUSSION

The present study explored the relationship between social support and psychological distress in parents of children with congenital heart disease (CHD) and revealed important insights into the caregiving experience in a South Asian context. Findings demonstrated that anxiety was the most prevalent psychological concern among parents, followed by stress and depression, which aligns with international evidence indicating that uncertainty regarding the prognosis of children with chronic illnesses often amplifies parental anxiety [14]. Contrary to some earlier research in Pakistan, which concluded depression to be the most important issue, the study indicates otherwise in relation to the patterns of psychology, which may be a product of the sociocultural interaction and processes in the family [15]. The research also found that there were no significant differences between the genders as regards psychological distress, which is contrary to the evidence of other parts of the world where mothers tend to be more distressed because of their traditional caregiving responsibility. This finding may indicate the change in cultural norms in the South Asian region, where fathers are more involved in caregiving roles. This gender equality indicates the changing care-giving patterns, which tend towards the approaches of shared parenting when providing care to children with CHD. These transformations point to the necessity to re-examine traditional beliefs about gendered caregiving within this cultural context [16]. Age was found to be a major factor which is related to

psychological distress. However, contrary to what some may have assumed, the older parents (18–28 years) experienced less stress, anxiety, and depression with the levels of distress tending to decline as the age of the parents increased. The result is in line with previous reports that younger parents might be more susceptible to disparate caregiving experiences, financial instability, and lower established coping practices. It can be assumed that the reduced distress levels in older parents may be explained by more substantial life experiences, advanced coping skills, and more stable socioeconomic status. These results underscore the need to support psychosocial interventions with the age-specific needs of caregivers [17]. Social support emerged as a critical protective factor against psychological distress. Family support was identified as the most significant source of assistance, consistent with previous research highlighting the centrality of extended family networks in South Asian cultures. However, an innovative finding of this study was that parents from nuclear families reported better psychological outcomes than those in joint family systems. This challenges the conventional belief that joint families always provide a supportive safety net, suggesting that interpersonal conflicts and lack of privacy within larger family structures may exacerbate caregiver stress [18]. Community and peer support were found to be less significant compared to family support, though still beneficial. This reflects cultural realities in South Asia where reliance on familial networks remains strong and peer-support structures are less developed compared to Western contexts. Previous literature from Western countries suggests that structured peer-support programs can significantly alleviate caregiver burden. The current findings suggest that while such programs may not replace familial support, they could be developed as complementary resources in South Asian societies to further reduce caregiver distress [19, 20]. The comparative analysis with broader literature reinforces that while global patterns of caregiver burden, such as stigma, financial stress, and emotional exhaustion, are consistent, the cultural context shapes the way social support moderates these burdens. The unique findings regarding gender equality in caregiving and the unexpected psychological outcomes of joint family systems provide new directions for research and interventions. These findings challenge assumptions rooted in cultural stereotypes and highlight the need for nuanced, context-specific approaches to supporting families of children with CHD [21]. Overall, this study makes a valuable contribution by situating the psychological experiences of parents within their sociocultural environment. It highlights the importance of recognizing shifting caregiving roles, addressing the

vulnerabilities of older parents, and reassessing the effectiveness of traditional family structures in providing support. The results suggest that healthcare systems and policymakers should focus on culturally sensitive interventions, including gender-inclusive programs, resources tailored for older caregivers, and the development of peer-support initiatives. By integrating these findings into practice, more effective strategies can be designed to alleviate caregiver distress and improve the quality of care for children with CHD and their families.

This study is limited by its cross-sectional design and reliance on self-reported measures, which may introduce bias and restrict causal inferences. Future research should include longitudinal studies across diverse regions in Pakistan, integrating both clinical assessments and qualitative insights. Such work could inform tailored psychosocial interventions and policies to strengthen parental support networks and improve mental health outcomes.

## CONCLUSIONS

In conclusion, this study highlights the critical role of social support from family, friends, and significant others in promoting psychological well-being among parents of children with congenital heart disease. Age, education, and family structure also influence mental health outcomes. Future research should further explore these relationships to develop personalized strategies that address the diverse needs of parents based on demographic and social factors.

## Authors' Contribution

Conceptualization: HU

Methodology: HU, SA, HA, SA, ID

Formal analysis: ID

Writing and Drafting: DM, HA, SH

Review and Editing: DM, HA, SH, ID, HU, SA

All authors approved the final manuscript and take responsibility for the integrity of the work.

## Conflicts of Interest

All the authors declare no conflict of interest.

## Source of Funding

The authors received no financial support for the research, authorship and/or publication of this article.

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