Original article

Quality of Life in Children with Congenital Birth Defects

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Submission Date : 14 June 2024
Accepted Date : 07 August 2024
Published Date : 30 September 2024
DOI: https://doi.org/10.3329/jrpmc.v9i2.77307

Abstract

Background:
Congenital birth defects are a leading cause of morbidity and mortality in children, with significant long-term impacts on health and quality of life (QoL).

Objective:
This study aimed to assess the quality of life (QoL) in children with congenital birth defects in Bangladesh, focusing on the influence of age, type of defect, and surgical interventions.

Methods:
This prospective cohort study was conducted at the Department of Pediatrics, 250 bedded General Hospital, Nilphamari, Bangladesh from July 2023 to June 2024. A total of 200 children aged 5-18 years with documented congenital anomalies were selected. Data were collected through medical record reviews and structured interviews using the Pediatric Quality of Life Inventory (PedsQL). Statistical analyses, including Chi-square tests and ANOVA, were employed to assess the relationships between QoL scores, age, type of defect, and surgical interventions.

Results:
The study revealed that the mean PedsQL scores decreased with age, with the lowest scores observed in the 16-18 years age group. Congenital heart defects were the most prevalent, affecting 40% of participants, followed by neural tube defects (20%) and cleft lip/palate (15%). Children with CHDs and neural tube defects had lower QoL scores compared to those with other defects. Additionally, 90% of participants underwent surgical interventions, with multiple surgeries associated with lower QoL.

Conclusion:
The study highlighted the significant impact of congenital defects on QoL, particularly among older children and those with more severe conditions like CHDs and neural tube defects. These findings underscored the need for targeted interventions to improve the long-term QoL of affected children.

Keywords: Congenital birth defects, Quality of life, Surgical interventions, Pediatric health, Bangladesh

Citation: Awyal MA. Quality of Life in Children with Congenital Birth Defects. J Rang Med Col. 2024 Sep;9(2):21-26.doi: https://doi.org/10.3329/jrpmc.v9i2.77307

Introduction:

Congenital birth defects, encompassing structural or genetic abnormalities, are significant contributors to health challenges and developmental issues in children. According to the Centers for Disease Control and Prevention (CDC), these defects remain a leading cause of neonatal mortality and long-term disabilities.[1] The World Health Organization reports that disability management research and education in low-income countries receive only 10% of global healthcare research funding, despite the critical

need for it.[2] Children born with congenital birth defects are at an increased risk of frequent hospitalizations, neurological disorders, and cognitive impairments compared to their peers.[3] The prevalence of these defects affects approximately 3-5% of live births worldwide, with varying trends observed in specific conditions. For example, while the prevalence of neural tube defects has decreased, cases of gastroschisis and trisomy have seen an uptick in recent years.[4,5] Congenital heart defects (CHDs) are prevalent congenital anomalies resulting from abnormal heart development during fetal life, affecting approximately 8 in 1,000 live births globally.[6] With over 150 million live births worldwide each year, around 1.35 million infants are born with congenital heart disease, making it one of the most prevalent congenital disorders.[7] Of these, about 25% present with complex forms of CHD, which are associated with high mortality rates.[8] Nevertheless, advances in medical care over the past 30 years have significantly improved survival rates, with over 85% of children with CHD now living into adulthood.[9] Despite these improvements, many children with CHD require ongoing medical care, including additional surgeries and interventions, due to the complexity of their condition.[10] Children with CHD face increased risk of neurodevelopmental delays, growth impairments, and other complications, affecting their quality of life.[11] This condition has become chronic, requiring continuous management. Transitioning into adulthood requires careful planning and support, posing challenges for affected children and their families, especially parents who often serve as primary caregivers.[12,13] The burden of caring for a child with congenital heart disease (CHD) can lead to increased stress, depression, and social isolation among parents, affecting the child's well-being.[14] This can strain the parent-child relationship and contribute to potential gender biases in caregiver interventions[15,16] highlighting the need for comprehensive data on how the quality of life for children with CHD influences and is influenced by the family unit over the long term.[17] The study aimed to evaluate quality of life for children with congenital birth defects in Bangladesh.

Methods:

This prospective cohort study was conducted at the Department of Pediatrics, 250 bedded General Hospital, Nilphamari, Bangladesh from July 2023 to June 2024. The study was conducted to examine the long-term outcomes and quality of life in children with congenital birth defects. A cohort of children aged 5-18 years, who had been diagnosed with congenital birth defects at birth, was selected from the study hospital. The study included children with documented congenital anomalies, completed at least five years, and consented parents, while exclusions included those with acquired conditions and no accessible medical records.

The study collected data through medical record reviews and structured interviews with children and their caregivers. It analyzed medical records to understand congenital defects, surgical interventions, hospitalizations, and complications. Interviews assessed health status, education, social integration, and quality of life. Standardized questionnaires like the Pediatric Quality of Life Inventory were used to measure quality of life. Quantitative data was analyzed using descriptive statistics, Chi-square tests, and ANOVA to compare quality of life scores across age groups and congenital defects. Qualitative data was thematically analyzed to identify recurring themes. Data was analyzed using SPSS version 26.

Results:

The study involved 200 participants, with a diverse age distribution, with 25% aged 5-8, 30% aged 9-12, 22.5% aged 13-15, and 22.5% aged 16-18 (Table-I).

Table-I: Demographic characteristics of participants (N=200)

Age group (Years)	no. (%)
5-8	50(25)
9-12	60(30)
13-15	45(22.5)
16-18	22.5

The study found that 40% of 200 participants had congenital heart defects, 20% had neural tube defects, 15% had cleft lip or palate, 10% had Down syndrome and limb deficiencies. (Figure-1)

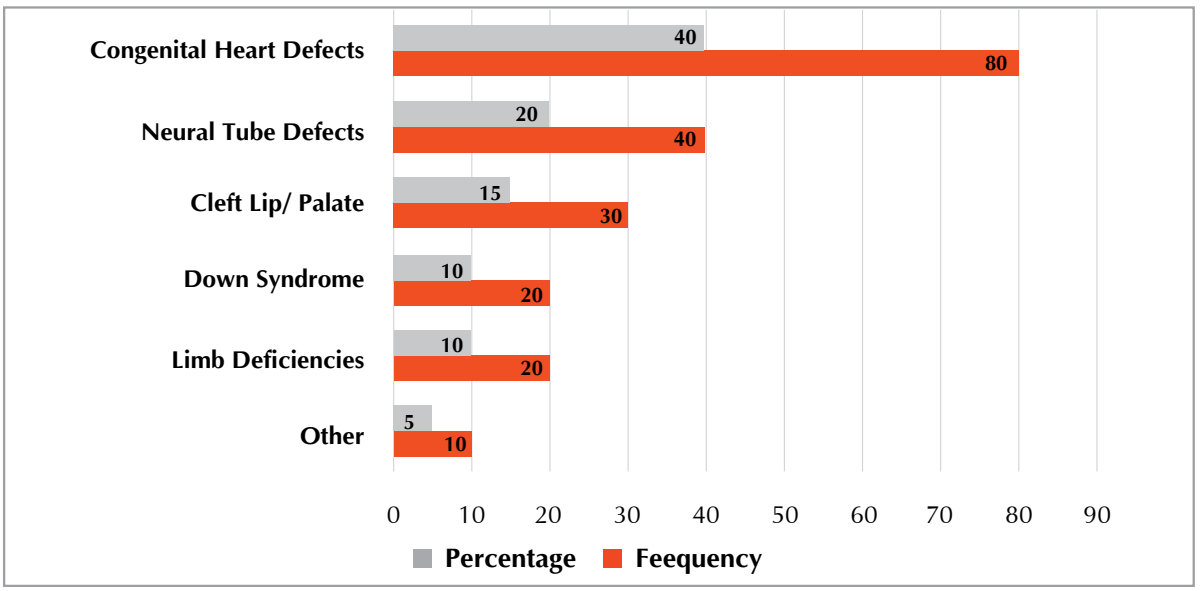
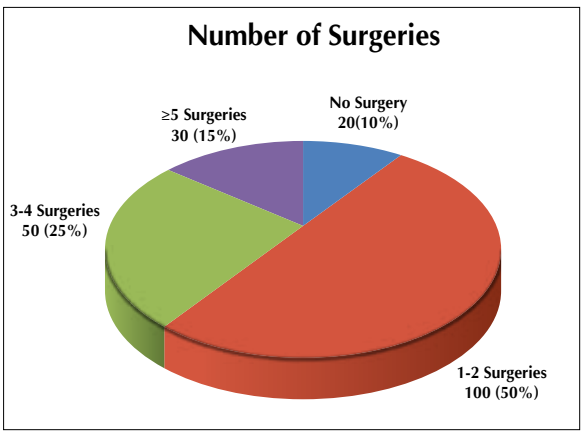


Figure-1: Distribution of congenital birth defects (N=200)

The study found that 90% of participants had at least one surgical procedure for congenital birth defects, with 50% requiring 1-2 surgeries, 25% requiring 3-4, and 15% requiring five or more surgeries (Figure-2).

Figure-2: Number of the surgical interventions (N=200)



The Pediatric Quality of Life Inventory (PedsQL) showed a decline in QoL scores with age, with the youngest age group (5-8 years) having the highest scores (78±10) and lowest in the 16-18 years group (65±18). QoL scores varied across different types of congenital birth defects, with congenital heart defects having the highest scores (72±14), neural tube defects having the lowest (68±15), cleft lip or palate had a mean score of 74±12 (Table-II).

Table-II: Quality of life scores by age group, type of defects and surgical interventions (N=200)

Variable	PedsQL Score (Mean±SD)	p-value
Age Range (years)		
5-8	78±10	
9-12	75±12	
13-15	70±15	<0.001
16-18	65±18	
Type of Defect		
Congenital Heart Defects	72±14	
Neural Tube Defects	68±15	
Cleft Lip/Palate	74±12	<0.001
Down Syndrome	70±16	
Limb Deficiencies	75±13	
Other	77±11	
Surgical interventions		
None	76±14	
1 to 2	72±09	<0.001
3 to 4	69±11	
5 or more	67±14	

Discussion:

The study evaluated the quality of life (QoL) of children with congenital birth defects in Bangladesh, focusing on age distribution, prevalence of different types of congenital defects, surgical interventions, and variations across age groups and defect types, providing a comparative perspective.

The age distribution of participants in this study was relatively balanced, with children spread across the 5-18 years age range. Notably, older children (16-18 years) exhibited the lowest mean Pediatric Quality of Life Inventory (PedsQL) scores, highlighting a decline in QoL with increasing age. This trend is consistent with findings from a study by Knowles et al, which reported that children with serious congenital heart defects (CHDs) experienced lower QoL compared to unaffected peers, particularly as they aged, due to the cumulative burden of clinical interventions and the psychosocial challenges associated with long-term management of CHDs.[18] The present study's observation of decreasing QoL scored with age underscores the need for age-specific interventions aimed at enhancing the quality of life in older children with congenital defects. Regarding the prevalence of congenital defects, congenital heart defects (CHDs) emerged as the most common anomaly in this cohort, affecting 40% of the participants. This finding was in line with the global trend observed in studies like those by Moreno-Medina et al and Sand et al, where CHDs were identified as a predominant congenital condition requiring complex medical management and often multiple surgical interventions.[19,20] The relatively high prevalence of neural tube defects (20%) and cleft lip/palate (15%) also aligned with previous research, which has documented these as significant contributors to morbidity in children with congenital anomalies.[21]The observed distribution of defects highlighted the importance of targeted healthcare strategies to manage the most prevalent conditions, particularly CHDs, which not only require intensive surgical care but also have a profound impact on the long-term QoL of affected children. The analysis of surgical interventions revealed that 90% of participants had undergone at least one surgical procedure, with a notable proportion requiring multiple surgeries. This high rate of surgical intervention mirrored findings from other studies that emphasize the critical role of surgery in managing congenital defects, particularly CHDs.[22] For instance, the study by Raj et al highlighted that children with uncorrected CHDs reported significantly lower QoL compared to controls, underscoring the importance of timely surgical intervention to mitigate the long-term impacts on QoL.[21] Moreover, the need for multiple surgeries, as observed in 40% of the participants in the present study, was indicative of the complexity and severity of these congenital conditions, which often necessitate ongoing medical and surgical management. The study also found significant variability in QoL scores based on the type of congenital defect. Children with CHDs and neural tube defects reported lower QoL scores compared to those with cleft lip/palate or limb deficiencies. This variability was consistent with the literature, where it has been documented that different types of congenital anomalies have varying impacts on the physical, emotional, and social aspects of a child's life. For example, Garcia Guerra et al. reported that children with both chromosomal abnormalities and CHDs had significantly lower QoL compared to healthy children, particularly in physical and psychosocial domains.[23] Similarly, Damiano et al found that the severity of speech and aesthetic concerns in children with cleft lip/palate significantly affected their QoL, particularly as they approached adolescence.[24] These findings suggested that while surgical interventions can improve certain aspects of life for children with congenital defects, the type of defect continues to play a crucial role in determining overall QoL outcomes. In summary, the findings from this study aligned with and expand upon existing research by providing a detailed analysis of QoL outcomes in children with congenital defects in Bangladesh. The comparative analysis underscored the need for defect-specific interventions, especially for conditions like CHDs and neural tube defects, where the impact on QoL was more pronounced. Furthermore, the observed decline in QoL with age highlighted the importance of continuous, age-appropriate support for children as they transitioned into adolescence and adulthood. Future research should focus on developing tailored interventions that address the specific needs of children with different types of congenital defects to improve their long-term QoL outcomes.

Limitations:
The study was conducted in a single hospital with a small sample size. So, the results may not represent the whole community.

Conclusion:
The findings of this study provide valuable insights into the long-term outcomes and quality of life (QoL) of children with congenital birth defects in Bangladesh. The study highlighted the significant impact that the type of congenital defect, the number of surgical interventions, and the child's age have on QoL. Children with congenital heart defects (CHDs) and neural tube defects were found to have lower QoL scores, particularly as they aged, emphasizing the need for continuous, age-specific, and condition-targeted support. The study underscored the importance of timely surgical interventions and the development of comprehensive healthcare strategies that address both the physical and psychosocial needs of children with congenital anomalies. These findings contribute to the growing body of evidence on the complexities of managing congenital defects and call for ongoing research and policy efforts to improve the overall well-being of affected children.

Funding: No funding sources

Conflict of interest: None declared

Ethical approval: The study was approved by the Institutional Ethics Committee

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