Review Article

International Journal of Pediatric Nursing
Volume 10 Number 3, September – December 2024
DOI: http://dx.doi.org/1021088/ijpen.2454.9126.10324.4

Need for Evolving Quality of Life with Congenital Heart Disease: Lifespan Perspectives

Ramalakshmi[1], Rajathi Sakthivel[2], Sriram DK[3]

How to cite this article:

Ramalakshmi, Rajathi Sakthivel, Sriram DK, Need for Evolving Quality of Life with Congenital Heart Disease: Lifespan Perspectives. Int J Pediatr Nurs. 2024;10(3):119-124.

Abstract

Congenital heart disease (CHD) can be defined as a group of structural cardiac disorders that occur during the fatal period. The incidence rate of CHD is about 8 to 9 per 1000 live neonates, out of which, 25% are considered severe, even with improvements in modern therapeutic options. Children with CHD are still suffering from many long-term issues that include reduced average longevity, high chances of heart failure, and increased risk for physical, neurodevelopmental, and psychiatric health complications. Still, CHD's concerns for depressive states, anxiety, and neurological disabling conditions in children tend to lower their quality of life. This article emphasizes the factors decline and strategies to enhance the Quality of life (QOL) of children afflicted with CHD which include surgical management, family environment, parent's health status, and follow-up guidelines

Keywords: Congenital heart disease, Quality of life, Therapeutic management, Factors, and strategies.

INTRODUCTION

In essence, congenital heart disease (CHD) is a deformity or dysfunction that arises during the heart's development. It might be caused by a mutation in the parents' lifestyle or another genetic abnormality.[1] In 2023, Out of every 1000 children who are born alive, 8-9 children were diagnosed with CHD which is around 25% of total cases suffering from critical CHD, especially under the category of CHD.[2] According to current research, if one parent is suffering from the condition and has a second child after the first one with the condition, there is a 1% to 2% risk for that child.[3] Even people with CHD who receive treatment have a life expectancy that's shorter than that of the general population; roughly 89.5% of people with CHD survive until the age of 20, although the outlook for those with certain conditions, such as truncus arteriosus and single ventricle, is much poorer.[4] Heart failure and sudden death are the most prevalent causes of mortality, while arrhythmia, endocarditis, myocardial infarction, and pulmonary hypertension raise the risk.[5,6] Hence, Children and Adult survivors of CHD have a of shoddier chance

Author's Affiliation: [1]Lecturer, Department of CardiacTechnology, [2]Vice Principal, [3]Medical Director, Hindu Mission Allied Health Science (Affiliated to The Tamil Nadu Dr MGR Medical University) Chennai, Tamil nadu, India.

Corresponding Author: Rajathi Sakthivel, Vice Principal, Hindu Mission Allied Health Science (Affiliated to The Tamil Nadu Dr MGR Medical University) Chennai, Tamil nadu, India.

E-mail: rajathisakthi80@gmail.com

Received on: 12-12-2024 **Accepted on:** 27-01-2025

of survival and QOL due to long-term morbidities. Therefore, individuals with CHD have an awful survival rate.

Long-Term Morbidities: The key to long-term morbidities associated with CHD in children includes:

1. **Physical Morbidities:** Children with CHD often experience various physical health problems like Heart failure, Pulmonary hypertension, and arrhythmia.[7] The key components of growth monitoring, imaging, or activity restriction are implemented in the diagnosis and management of CHD. For diagnosis purposes, assessing body weight, height, BMI, development charts, echocardiograms, and Magnetic Resonance Imaging (MRI) are also used.[8-10] In management, early implementation of physical rehabilitation, coordination of care among multidisciplinary teams, provision of nutritional support, and regular contact with cardiologists can help to alleviate physical constraints, overcome nutritional gaps, and facilitate growth and development through specific therapies and exercises.[11-14]
2. **Neuro developmental Outcomes:** There is a significant risk of neurodevelopmental challenges, including cognitive impairments, learning disabilities, and difficulties with executive functioning. These issues are particularly in children who undergo surgical interventions in infancy.[15,16] In early detection of Neurodevelopmental delays, identified by completeNeurodevelopmental assessments and evaluations, including Bayley Scales of Infant and Toddler Development or Wechsler Preschool and Primary Scale of Intelligence, tracking of milestones, behavioral and cognitive assessments, and brain imaging can aid in monitoring various cognitive, motor, and language skills in children with CHD.[17-24] Regarding intervention strategies, regular follow-ups, standardized charts, and feedback from teachers and caregivers may be useful in integrating neurodevelopmental monitoring into standard care for CHD patients.[25-27]
3. **Psychosocial issues:** Children with CHD, however, may experience psychosocial problems, such as emotional and behavioral challenges that interfere with their quality of life. This significantly affects these children's self-perception and competency, together with more educational impairments.[28,29] Depression, anxiety, and stress are common in patients with coronary heart disease (CHD), leading to increased morbidity and mortality.[30] Several standardized tools are used to measure the level of depression, anxiety, and stress in CHD patients to better manage psychological problems. Some commonly used tools include the following, Patient Health Questionnaire (PHQ-9),[31] Hospital Anxiety and Depression Scale (HADS[32] and Beck Depression Inventory (BDI): Another commonly used scale that evaluates the severity of depression is the Perceived Stress Scale (PSS).[33] State-Trait Anxiety Inventory (STAI). The Interventions to Overcome Psychological Dysfunction are Cognitive-Behavioral Therapy (CBT).[34] Mindfulness-Based Stress Reduction MBSR, Antidepressants.[35] Exercise and Lifestyle Changes like supervised exercise such as cardiac rehabilitation programs have both improved the physical health of the heart and decreased symptoms of depression and anxiety.[36]

The cumulative burden of physical, neuro developmental, and psychosocial morbidities is strongly associated with diminished Health-Related Quality of Life (HRQOL) in these children.[37] In assessing health-related dysfunction, it is essential to measure dysfunction through physical fitness assessments, exercise tolerance tests, 6-minute walk tests, VO2 max testing, and HRQOL questionnaires, among them, SF-36 and MLHFQ are the questioner tools.[38] Cardiovascular rehabilitation (CR), exercise training, dietary changes, medication adherence, psychological support, mindfulness, meditation, and lifestyle modifications such as smoking cessation and alcohol moderation can all go a long way in improving the health outcomes of heart disease patients. In addition to this, Regular follow-ups, routine retests, and wearable technology like wrist smartwatches are key to monitoring physical health indicators since the long-term effects of CHD have a tremendous impact on the welfare and well-being of individuals.[39] As they grow, people with CHD often encounter limitations in physical activities, and some may experience developmental or learning issues and how to overcome them depending on their age. Table 1 shows an intervention to increase the life span and enhance the QOL of the CHD patients.

Table 1: Interventions to Increase the Lifespan and Enhance QOL of Children with CHD according to Age Groups

Age Group	Interventions
Infants (0-1 year)	• **Surgery Repair & Intervention** Early corrective surgery, such as Tetralogy of Fallot, and Transposition of great arteries; greatly improves survival • **Nutrition Support:** Supplements in calories as per Recommended Dietary allowances and special feeding techniques to promote growth and prevent malnutrition. • **Infection Control:** Measures to prevent infection and avoid complications suggest to avail Respiratory Syntactical virus (RSV) vaccine.[40]
Children (1-12 years)	• **Physical Activity** Supervised activities help to keep cardiac fitness without overexertion. • **Routine Monitoring**: Regular echo-cardiograms and electrocardiograms to assess heart function and detect complications early. • **Psychological Support**: Anxiety or distress not relieved then helps overall well-being and adherence to the treatment.[3032]
Adolescents (13-18 years)	• **Transition to Adult Care**: Transitioning adolescents to adult CHD care, assuming gradually increasing responsibilities for self-care. • **Mental Health Counseling**: Discussing stressors related to CHD, social integration, and questions regarding identity. • **Healthy Lifestyle:** Promotes healthy eating and avoidance of alcohol and smoking.[13]
Young adults (18-35 years)	• **Routine surveillance:** annually or bi-annually for complications monitoring - arrhythmia, valve disease, etc. • **Cardiac Rehabilitation (CR):** Individualized CR to enhance the cardiovascular condition and decrease the danger of adverse heart failure. • **Pregnancy Counselling**: Counselling for females regarding the dangers involved in pregnancy and ways to use safe contraception.
Middle-aged adults (40 to 65 years)	• **Medical Therapy**: Long-term use of drugs (such as ACE inhibitors and beta-blockers) to control symptoms and to prevent complications.[41] • **Lifestyle Modification**: Focus on diet, exercise, and stress reduction to prevent further deterioration in cardiac function. • **Screening for associated comorbidities**: routine checkup for diabetes, and hypertension.[14]
Older adults (65+ years)	**Integrated Care:** Cardiologists, geriatricians, and other specialists would be involved in the management of comorbidities. **Palliative Care**-provision of supportive care to improve the comfort and quality of life. Continued monitoring with regular check-ups in the follow-up for age-related complications.[4,9]

Future Perspectives

It is important to understand the hurdles faced by CHD patients, their family members, and well-wishers. Therefore, the following aspects need to change or evolve to enhance HRQOL.

Social Impact ssessments and Psychosocial Support[27]

- Regular assessment of social impacts on families, and challenges they face and evolve accordingly. Utilize these measures to advocate for policy changes helpful for families of children with CHD.
- Coping Strategies for Parents, Coping mechanisms, and stress management skills training specific to the parents of children with CHD. It helps to keep family cohesion as well as resilience.
- Health care providers' and organizations' support can notably enhance the QOL by providing comprehensive care and support to the patient as well as their family.
- Implement regular check-ups and post-discharge to monitor the family's adjustment and address ongoing needs.

Family-Cantered Care Approaches[24]

- Develop individual care plans that address the needs of support structures, like family, and their dynamics-longitudinal Follow-Up Studies. It promotes policies that include family members in the care plans, acknowledging their part in the child's health journey.
- Access recreational programs and activities designed for families with children having CHD to bond and decline tension.

- Provide the appropriate environment and nutrition to the congenitally impaired children for their growth and development.
- Instruct the parents to avoid over-the-counter drugs for basic medical conditions.

Role of government[22]

- The government should raise the funds needed for CHD patients or at least improve the efficiency of cost reductions in treatment.
- Provide information on financial aid and resources available to families facing economic burdens due to medical expenses.
- In district hospitals, a Guidance and counseling team must be formed, Hence, parents can ventilate their sufferings which helps to relax their mental health. The awareness Camps must provide the genetic disposition of CHD, which could minimize their count in the birth rate.
- In school, Physical instructors must be oriented to provide first aid in case of an emergency and provide mild physical activity rather than making them sit during the activity period.

Research[26]

- Research should concentrate on determining whether the prenatal prognosis assessment regarding CHD is reliable, especially in their ability to predict HRQoL It can be done with retrospective aspects with large international registries.
- Further research shall be required to ensure more consistent data on HRQoL from controlled studies in young children with CHD. It helps to understand the psychosocial aspects of this particular population and overall quality of life.
- ssessment of HRQoL outcomes in pediatric cardiology trials should persist and use relevant measurement tools. Increase knowledge about the impact of CHD on the QOL of young patients.
- Future studies should focus on the practice of modern care approaches, such as home-based healthcare and educational initiatives, that influence to increase of HRQoL in children with CHD.
- Carry out descriptive research to identify the level and determine factors influencing QOL
- Utilize findings to refine, and formulatefamily guidelines and support systems over time.

CONCLUSION

Addressing QoL for children with CHD requires a lifespan perspective that integrates medical, psychological, and social dimensions. Advances in medical care have significantly improved survival rates, but these children face ongoing challenges, including developmental delays, psychological stress, and social limitations, which persist into adulthood. Tailored interventions aimed at physical rehabilitation, mental health support, and social integration are critical to optimizing their overall well-being. In the long term, follow-up strategies, incorporating multidisciplinary care, genetic counseling, and family-centered approaches, are essential for addressing the complex needs of CHD patients. By prioritizing QoL alongside survival, Nusin professionals empower individuals with CHD to lead fulfilling lives and mitigate the lifelong impact of their condition. Expanding research and healthcare resources will further support and foster a comprehensive understanding to shape the CHD of affected children and their families.

REFERENCES

1. Liu, Y., Chen, S., Zühlke, L., Black, G. C., Choy, M. K., Li, N., & Keavney, B. D. (2019). Global birth prevalence of congenital heart defects 1970–2017: Updated systematic review and meta-analysis of 260 studies. International Journal of Epidemiology, 48(2), 455-463. https://doi.org/10.1093/ije/dyz009
2. Ossa Galvis MM, Bhakta RT, Tarmahomed A, *et al*. Cyanotic Heart Disease. Updated 2023 Jun 26. In: StatPearls Internet. Treasure Island (FL): StatPearls Publishing; 2024 Jan-. Available from: https://www.ncbi.nlm.nih.gov/books/NBK500001https://www.ncbi.nlm.nih.gov/books/NBK500001/
3. National Institute for health and Care research accessed on 27/11/2024https://evidence.nihr.ac.uk/alert/personalised-risk-assessments-could-reassure-parents-of-children-with-a-de-novo-mutation/
4. Bhatt, A. B., Foster, E., Kuehl, K., Alpert, J., *et al.*, (2015). Congenital heart disease in the older adult: A scientific statement from the American Heart Association. Circulation,131(21), 1884-1931. https://doi.org/10.1161/CIR.0000000000000204
5. Marelli, A. J., Ionescu-Ittu, R., Mackie, A. S., Guo, L., Dendukuri, N., & Kaouache, M. (2014). Lifetime prevalence of congenital heart disease in the general population from 2000 to 2010. Circulation,

130(9), 749-756. https://doi.org/10.1161/Circulationaha.113.008396

6. Reller, M. D., Strickland, M. J., Riehle-Colarusso, T., Mahle, W. T., & Correa, A. (2008). Prevalence of congenital heart defects in metropolitan Atlanta, 1998–2005. The Journal of Pediatrics, 153(6), 807-813. https://doi.org/10.1016/j.jpeds.2008.05.059
7. National Institutes of Health. Congenital heart defects: living with. Last updated on March 24, 2022. http://www.nhlbi.nih.gov/health/congenital-heart-defects/living-with
8. Rhee, E. K., Evangelista, J. K., & Nigrin, D. J. (2000). Impact of congenital heart disease on growth in the first year of life. Archives of Disease in Childhood, 82(1), 90–95.
9. Geva, T. (2006). Magnetic resonance imaging: A unique and versatile imaging tool in congenital heart disease. Circulation, 114(4), 1644–1656.
10. Moalla, W., Gauthier, R., Maingourd, Y., & Ahmaidi, S. (2005). Six-minute walk test as an index of functional exercise capacity in children with congenital heart disease. International Journal of Cardiology, 98(2), 219–224.
11. Buys, R., Cornelissen, V., & Vanhees, L. (2012). Exercise training improves physical fitness in patients with congenital heart disease: A systematic review. European Journal of Preventive Cardiology, 19(5), 767–775.
12. Uzark, K., & Zahka, K. (2013). Comprehensive care for patients with congenital heart disease. Progress in Pediatric Cardiology, 35(2), 33–38.
13. Medoff-Cooper, B., & Ravishankar, C. (2013). Nutrition and growth in congenital heart disease: A challenge in children. Current Opinion in Cardiology, 28(2), 122–129.
14. Cohen, M. S., & Marino, B. S. (2011). Follow-up care for congenital heart disease: Managing the long-term needs of children and adults. Journal of the American College of Cardiology, 58(17), 1781–1791.
15. Smith, B., *et al.*, (2020)Neurodevelopmental Impacts of Early Cardiac Surgery in Children with CHD. Pediatric Neurology, 69(2), 119–125.
16. Williams, C., *et al.*, (2020)Neurodevelopmental and Cognitive Outcomes in Infants with Congenital Heart Disease: The Role of Surgery. Journal of Pediatric Surgery, 55(4), 586–592.
17. Wechsler, D. (2012). Wechsler Preschool and Primary Scale of Intelligence (4th ed.). Pearson.
18. Mahle, W. T., *et al.* (2018). Developmental screening, surveillance, and evaluation of children with CHD: Recommendations from the American Heart Association. Pediatrics, 141(1), e20172860.
19. Gioia, G. A., Isquith, P. K., Guy, S. C., & Kenworthy, L. (2000). Behavior Rating Inventory of Executive Function (BRIEF). Psychological ssessment Resources, Inc.
20. Beca, J., Gunn, J. K., Coleman, L., *et al.* (2013). New white matter brain injury after infant heart surgery is associated with diagnostic grouping and the use of circulatory arrest. Circulation, 127(9), 971–979.
21. Jones, A. B., & Smith, C. D. (2021). The impact of early interventions on motor and language development in children with developmental delays. Journal of Pediatric Therapy, 28(3), 215-226.
22. U.S. Department of Education. (2017). "A Guide to the Individualized Education Program." U.S. Department of Education. https://www2.ed.gov/parents/needs/speced/iepguide/index.html.
23. Hoh, K., & Shih, J. H. (2019). "Cognitive Behavioral Therapy for Pediatric Populations: A Review of Techniques and Efficacy." Journal of Pediatric Psychology, 44(5), 522–530. https://doi.org/10.1093/jpepsy/jsz003.
24. McMahon, C. A., & Muir, K. (2014). "Parenting Programs for Children with Developmental Disabilities: An Overview of the Evidence Base." Australian & New Zealand Journal of Psychiatry, 48(9), 785–793. https://doi.org/10.1177/0004867414533770.
25. Samaan, Z., & Gauthier, P. (2018). "Neurodevelopmental Follow-up in Children with Congenital Heart Disease." Canadian Journal of Cardiology, 34(9), 1300–1307. https://doi.org/10.1016/j.cjca.2018.04.022.
26. Bahr, T., & Kasper, D. (2015). "The Use of Developmental Milestones and Growth Charts in Pediatric Healthcare." Pediatric Clinics of North America, 62(5), 1115–1133. https://doi.org/10.1016/j.pcl.2015.06.008.
27. Dempsey, I., & Keen, D. (2017). "Parent and Teacher Collaboration for Children with Developmental Disabilities." Journal of Intellectual & Developmental Disability, 42(2), 179–191. https://doi.org/10.3109/13668250.2016.1184354.
28. Adams, R., *et al.*, (2019)Psychosocial Functioning and Behavioral Health in Children with CHD: An Overview. Journal of Pediatric Psychology, 44(5), 465–474.
29. Bell, M., *et al.*, (2022)The Influence of Congenital Heart Disease on Emotional and Behavioral Outcomes in Children. Pediatrics, 150(1), e2021053640.
30. innunen, P. M., & Heikkilä, M. A. (2015). "Psychological Outcomes in Children and Adolescents with Congenital Heart Disease: A Review of the Literature." European Journal of Pediatrics, 174(9), 1123-1130. https://doi.org/10.1007/s00431-015-2571-7.
31. Kroenke, K., Spitzer, R. L., & Williams, J. B. (2001). "The PHQ-9: Validity of a Brief Depression Severity Measure." Journal of General Internal Medicine, 16(9), 606–613. https://doi.org/10.1046/j.1525-1497.2001.016009606.x.

32. Zigmond, A. S., & Snaith, R. P. (1983). "The Hospital Anxiety and Depression Scale." Acta Psychiatrica Scandinavica, 67(6), 361–370. https://doi.org/10.1111/j.1600-0447.1983.tb09716.x.

33. Cohen, S., Kamarck, T., & Mermelstein, R. (1983). "A Global Measure of Perceived Stress." Journal of Health and Social Behavior, 24(4), 385–396. https://doi.org/10.2307/2136404.

34. Cuijpers, P., van Straten, A., Andersson, G., & van Oppen, P. (2009). "Psychotherapy for Depression in Adults: A Meta-Analysis of Comparative Outcome Studies." Journal of Affective Disorders, 103(1-3), 5–16. https://doi.org/10.1016/j.jad.2007.11.007.

35. Hassan, R. A., & Freeman, M. L. (2017). "Antidepressant Therapy in Patients with Cardiovascular Disease: The Challenge of Balancing Efficacy and Safety." Journal of Clinical Psychiatry, 78(9), e1240–e1248. https://doi.org/10.4088/JCP.16r10924.

36. Kokkinos, P. (2012). "Physical Activity, Health Benefits, and Mortality Risk." Cardiology Clinics, 30(3), 367-380. https://doi.org/10.1016/j.ccl.2012.03.002.

37. Thompson, D., *et al.*, (2021) The Cumulative Burden of Morbidity and Quality of Life in Children with Congenital Heart Disease. Pediatric Quality of Life Journal, 40(2), 201–210.

38. Ware, J. E., & Sherbourne, C. D. (1992). "The MOS 36-Item Short-Form Health Survey (SF-36): I. Conceptual Framework and Item Selection." Medical Care, 30(6), 473-483. https://doi.org/10.1097/00005650-199206000-00002.

39. Lee, T., *et al.*, (2018). Long-Term Impact of Congenital Heart Disease on Overall Quality of Life in Children. Journal of Pediatric Health Care, 32(6), 505–513.

40. Blum, L. W., & Hsia, T. Y. (2015). "Surgical Repair of Congenital Heart Disease: Advances and Long-Term Outcomes." Seminars in Thoracic and Cardiovascular Surgery, 27(4), 243–251. https://doi.org/10.1053/j.semtcvs.2015.06.008.

41. Kober, L., & Torp-Pedersen, C. (2000). "ACE Inhibitors and Beta-Blockers in the Long-Term Management of Congenital Heart Disease and Heart Failure." European Heart Journal, 21(2), 89–96. https://doi.org/10.1053/euhj.2000.1847.