

Quality of Life and Financial Burden in Congenital Heart Disease Care: A Large-Scale Survey of Pre- and Post-Treatment Outcomes in a Free Tertiary Hospital

Shadab Ahamad¹, Mahima Sharma¹, C. Sreenivas¹, Gaurav Bhardwaj², Anagha Tulsi², Prachi Kukshal¹

¹Sri Sathya Sai Sanjeevani Research Centre, Palwal, Haryana, India

²Sri Sathya Sai Sanjeevani International Centre for Child Heart Care and Research, Palwal, Haryana, India

INTRODUCTION

- Congenital heart disease (CHD) is the most common birth defect globally, imposing substantial physical, emotional, and social burdens on affected children and their families.
- Although advances in pediatric cardiac surgery have improved survival, quality-of-life (QoL) outcomes, particularly in low-resource settings, remain underexplored. ^[1]

Figure 1: Need-Supply Gap in Pediatric Cardiac Care ^[2]

SCREENING	INTERVENTION	PREVENTION
<ul style="list-style-type: none"> Lack of Awareness Delayed Diagnosis 	<ul style="list-style-type: none"> High Patient Volume Un-availability In-accessibility Un-affordability 	<ul style="list-style-type: none"> Lack of Research Malnutrition

- Free tertiary referral hospitals offer an opportunity to assess the impact of equitable access to advanced cardiac care.

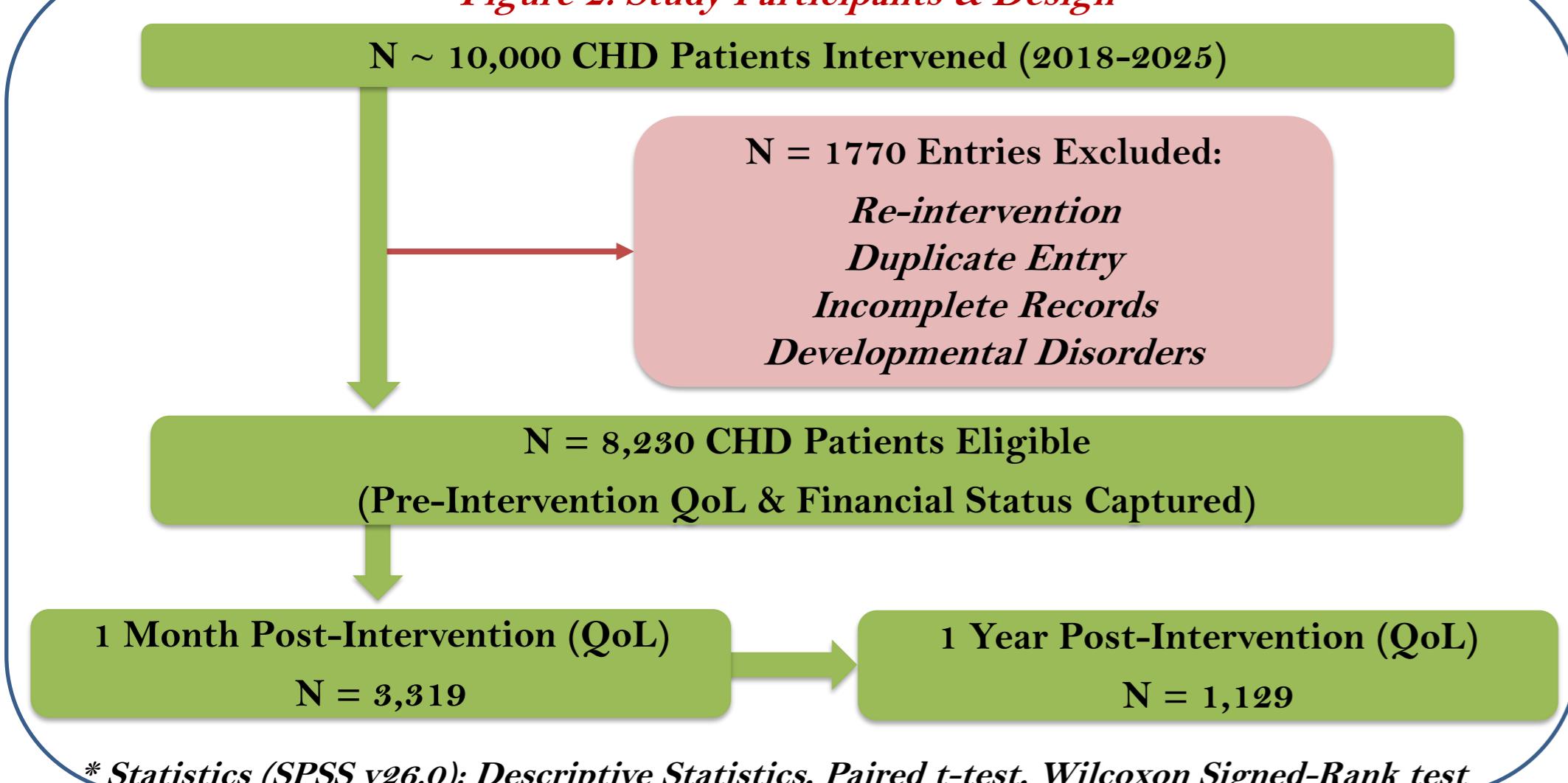
OBJECTIVE

To evaluate the QoL of families of CHD patients before and after intervention, with emphasis on psychosocial wellbeing and financial burden.

METHODOLOGY

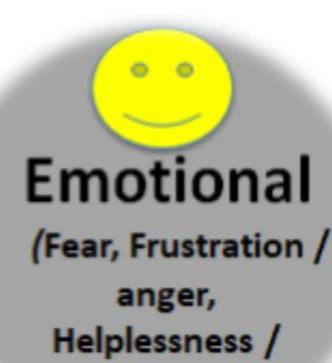
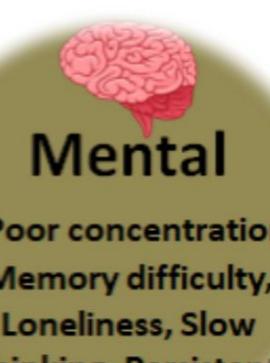
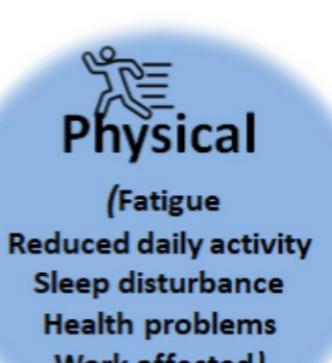
- Design: Retrospective-Longitudinal Cohort Study
- Participants: Caregivers of patients who underwent intervention for CHD
- Site: Sri Sathya Sai Sanjeevani Hospital-A free-of-cost tertiary cardiac center (India)

Figure 2: Study Participants & Design



* Statistics (SPSS v26.0): Descriptive Statistics, Paired t-test, Wilcoxon Signed-Rank test

- Assessments:
 - CHD: Echocardiography, and categorized based on: ^[3]
 - Severity: Simple and Complex CHD
 - Systemic Hypoxia: Cyanotic and Acyanotic CHD
 - QoL: 20-item in-house questionnaire, across 4 stress domains



- Response: Four-point Likert Scale (Never, Sometimes, Often, and Always)

- Financial Burden: Assessed via:
 - Subjective Method (to Manage Intervention Cost): Response based Fully Fund | Partially Fund | Incurring Debt | Wouldn't proceed
 - Calculative Method: Based on Annual Income and Intervention Cost
 - <25% → Low Financial Stress
 - 25-50% → Moderate Financial Stress
 - >50-75% → High Financial Stress
 - >75% → Extreme Financial Stress



RESULTS & DISCUSSION

Figure 3: Overall Pre-Intervention QoL-related Stress & Socioeconomic Status^[4] of Family

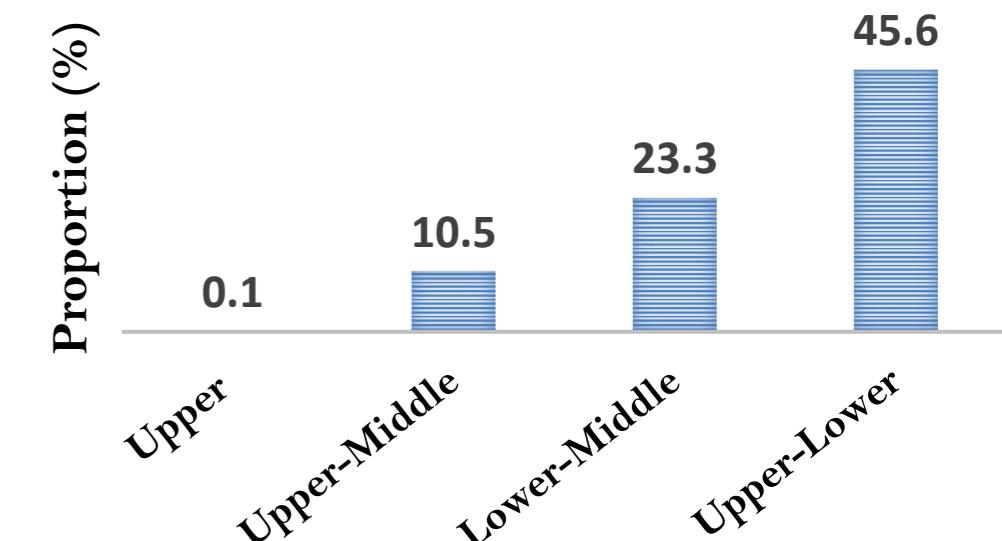
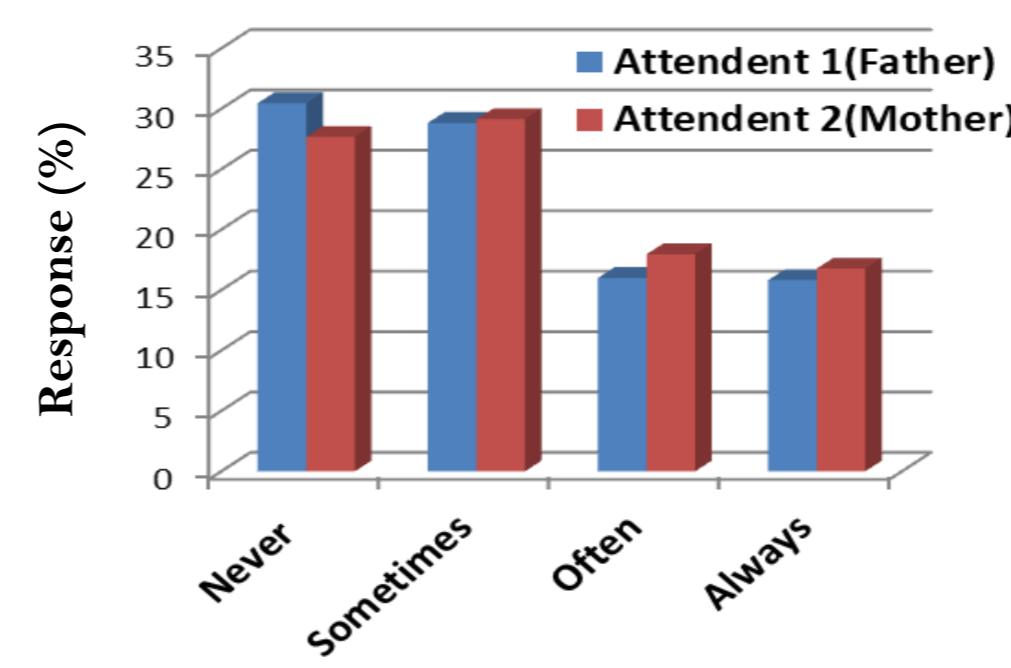
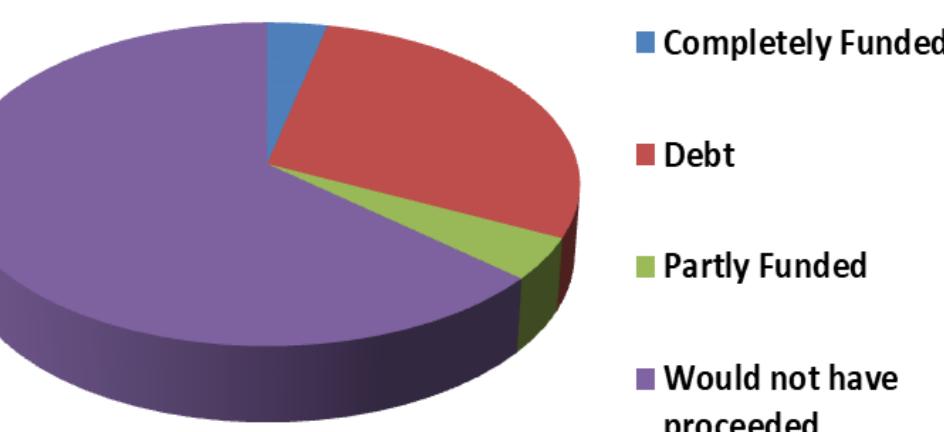
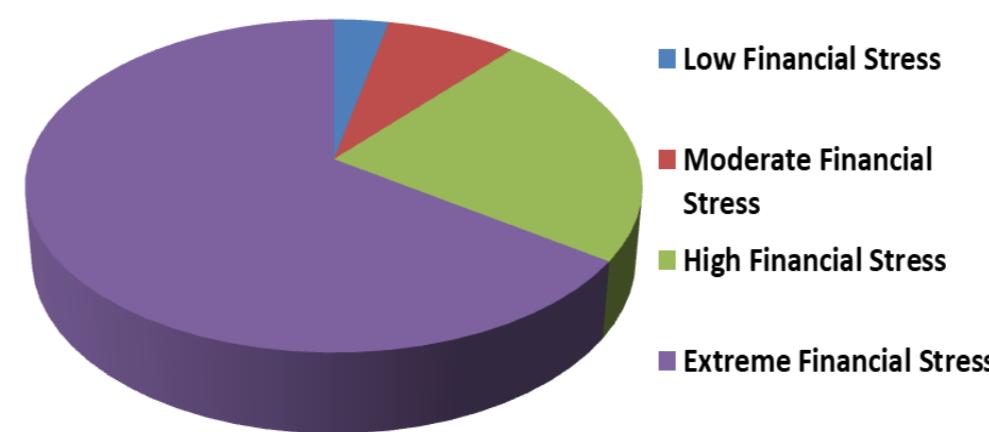


Figure 4: Financial Burden among CHD Families: Cost Affordability Measure



[A] Based on Income (Calculative)

[B] Based on Response (Subjective)

Table 1: Pre- Vs Post-Intervention QoL Improvement: Impact of Free Cardiac Centre

Domains	Acyanotic CHD ^{\$}	Cyanotic CHD ^{\$}	Simple CHD ^{\$}	Complex CHD ^{\$}	Effect Size	p value ^{&}
Physical Health	174.5% ↑	232.5% ↑↑	164.0% ↑	200.3% ↑↑	0.89	<0.001***
Social Health	178.1% ↑↑	213.3% ↑↑	172.6% ↑	183.5% ↑↑	0.82	<0.001***
Mental Health	180.4% ↑↑	221.2% ↑↑	172.1% ↑	191.0% ↑↑	0.87	<0.001***
Emotional Health	157.4% ↑	198.1% ↑↑	155.0% ↑	174.4% ↑	0.83	<0.001***

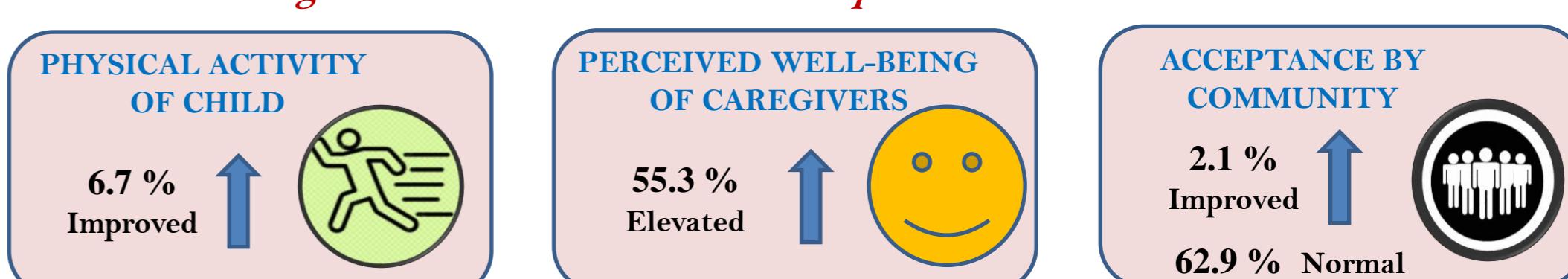
[&]Wilcoxon Signed-Rank Test | ^{\$}Values are represented as relative improvement (%)

Table 2: Post-Intervention Growth Chart of Patients

Age group	At 1 Month Follow-up (p value ^④)			At 1 Year Follow-up (p value ^④)		
	Height	Weight	BMI	Height	Weight	BMI
≤ 1 Y	0.301	<0.001***	0.330	0.025*	0.270	<0.001***
>1 to 5 Y	<0.001***	0.528	0.305	0.004**	<0.001***	<0.001***
>5 to 12 Y	<0.001***	<0.001***	0.157	<0.001**	<0.001***	<0.001***
≥ 12 Y	0.507	0.043*	0.804	0.002**	<0.001***	<0.001***

^④Paired t-Test

Figure 5: Others Determinants Improved 1 Year Post-Intervention



CONCLUSION

- Treatment of CHD in a no-cost tertiary setting significantly improves QoL, extending benefits beyond clinical recovery to psychosocial and financial wellbeing.
- It underscore the impact of equitable access to advanced cardiac care in reducing hardship and promoting health equity, while acknowledging that the one-third postoperative response rate may introduce response bias affecting generalizability.
- Comprehensive inclusion of indirect and catastrophic health expenditures will further inform health policy and support expansion of free pediatric cardiac care programs.

REFERENCES

- [1] Ali F, et al. *J Soc Cardiovasc Angiogr Interv.* **2025**;4(12):103922. doi:10.1016/j.jscai.2025.103922
- [2] Ahamad S, et al. *Ann Natl Acad Med Sci.* **2025**; 61: 40-4. doi: 10.25259/ANAMS_242_2024
- [3] Meng X, et al. *MedComm.* **2024**; 5(7): e631. doi: 10.1002/mco2.631
- [4] Mohanty M, et al. *Prev Med Res Rev.* **2024**; 1(3): 166-167. doi: 10.4103/PMRR.PMRR_28_24