

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

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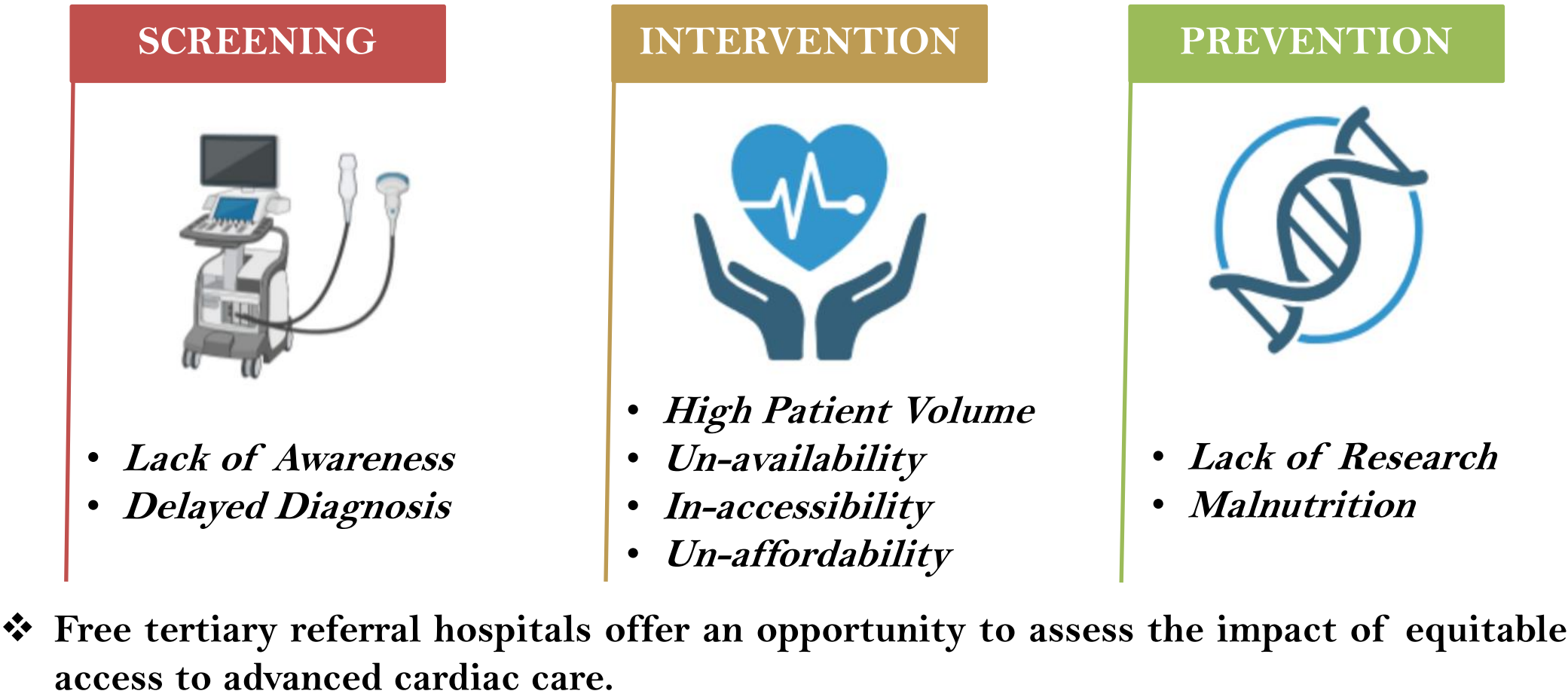
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INTRODUCTION

- ❖ *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.* <sup>[1]</sup>

Figure 1: Need-Supply Gap in Pediatric Cardiac Care <sup>[2]</sup>



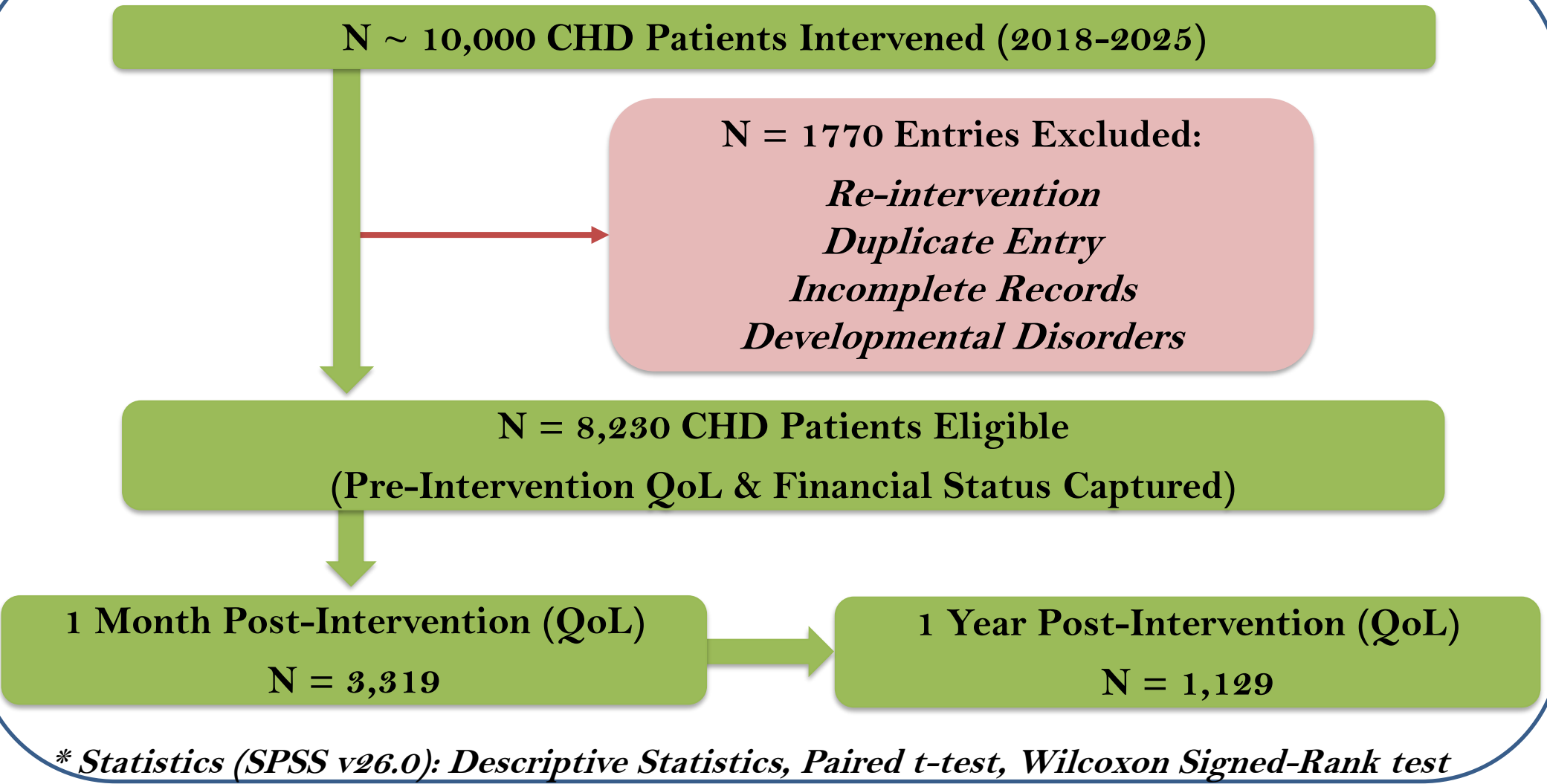
OBJECTIVE

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

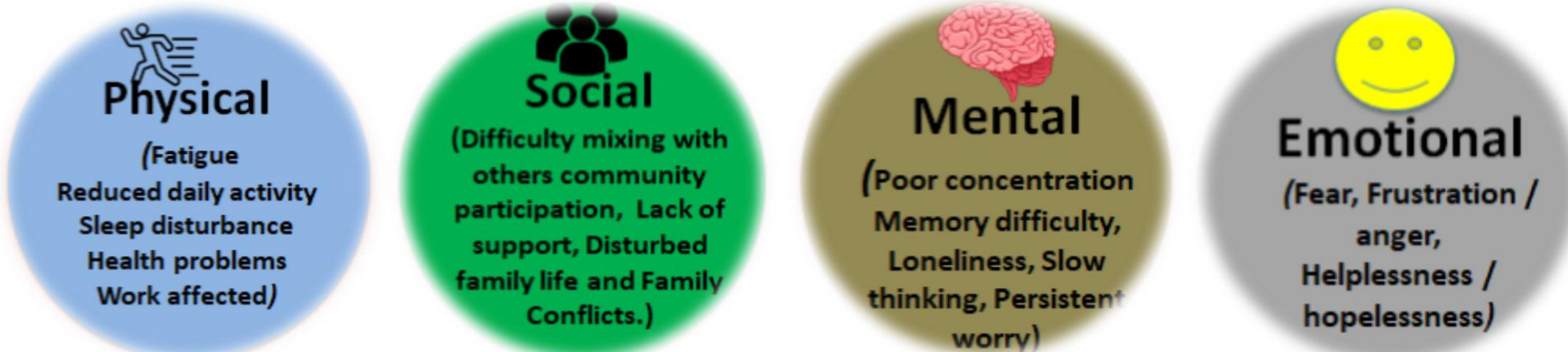
METHODOLOGY

- ❖ 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



- ❖ Assessments:
  - ✓ CHD: Echocardiography, and categorized based on: <sup>[3]</sup>
    - 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<sup>[4]</sup> of Family

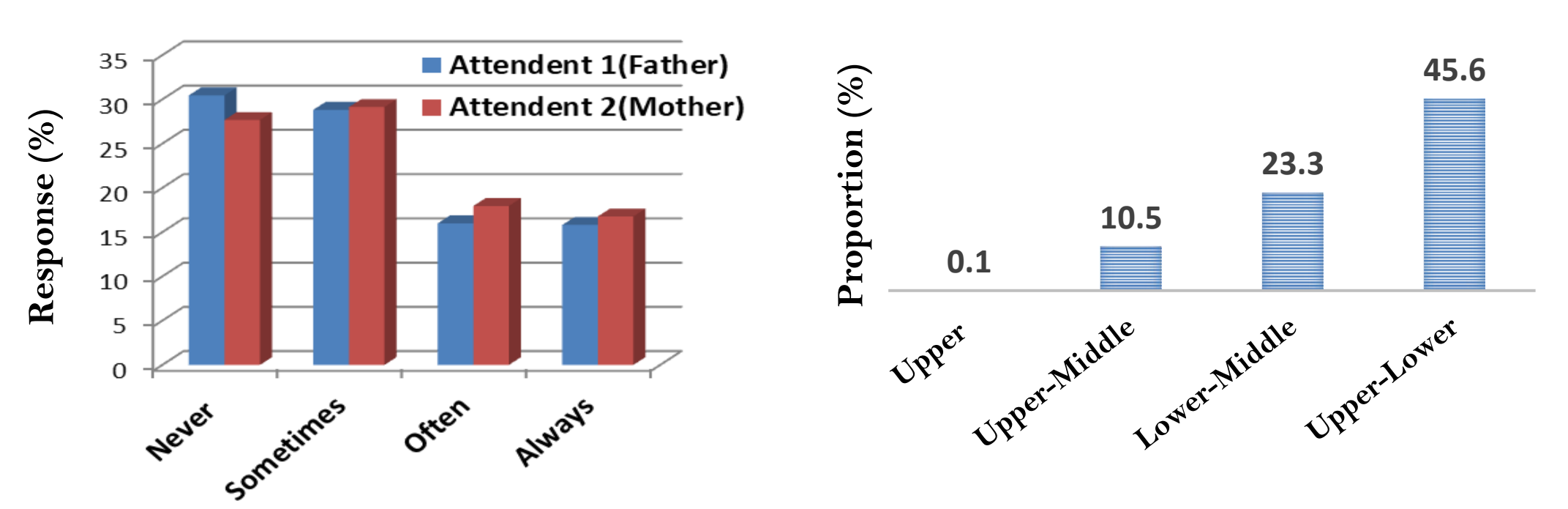


Figure 4: Financial Burden among CHD Families: Cost Affordability Measure

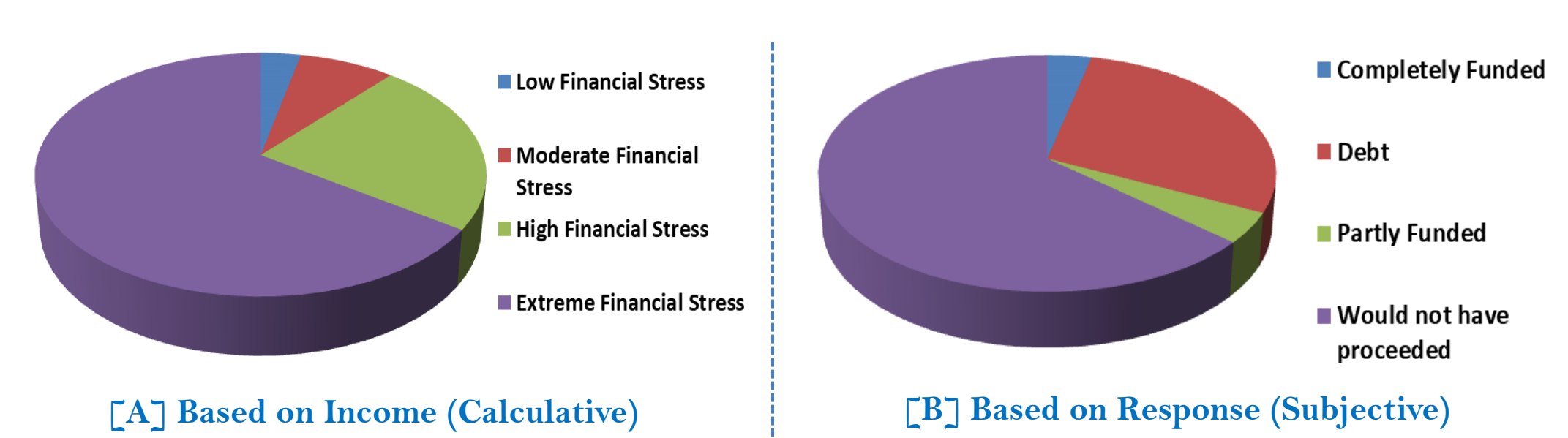


Table 1: Pre- Vs Post-Intervention QoL Improvement: Impact of Free Cardiac Centre

Domains	Acyanotic CHD <sup>§</sup>	Cyanotic CHD <sup>§</sup>	Simple CHD <sup>§</sup>	Complex CHD <sup>§</sup>	Effect Size	<i>p</i> value <sup>&amp;</sup>
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***

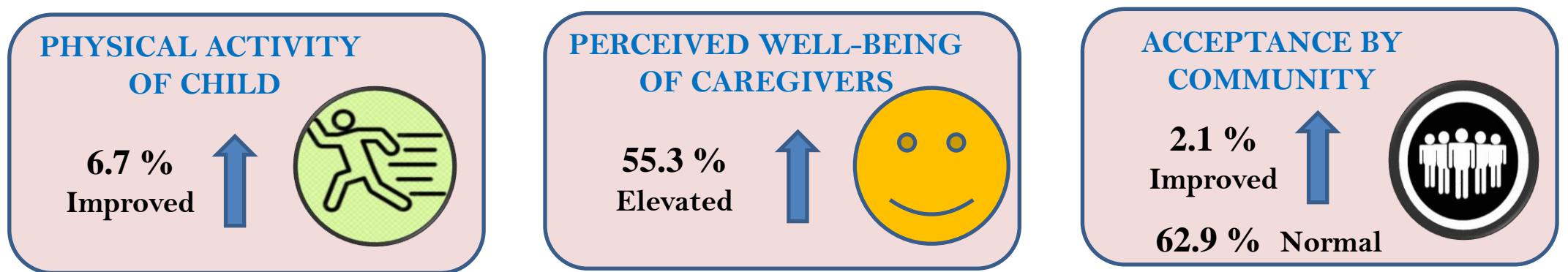
<sup>&</sup> Wilcoxon Signed-Rank Test | <sup>§</sup> Values are represented as relative improvement (%)

Table 2: Post-Intervention Growth Chart of Patients

Age group	At 1 Month Follow-up ( <i>p</i> value <sup>@</sup> )			At 1 Year Follow-up ( <i>p</i> value <sup>@</sup> )		
	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***

<sup>@</sup> Paired *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.

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