Health related quality of life in post-operative congenital heart disease adults: a mixed methods study from a low middle income country, Pakistan

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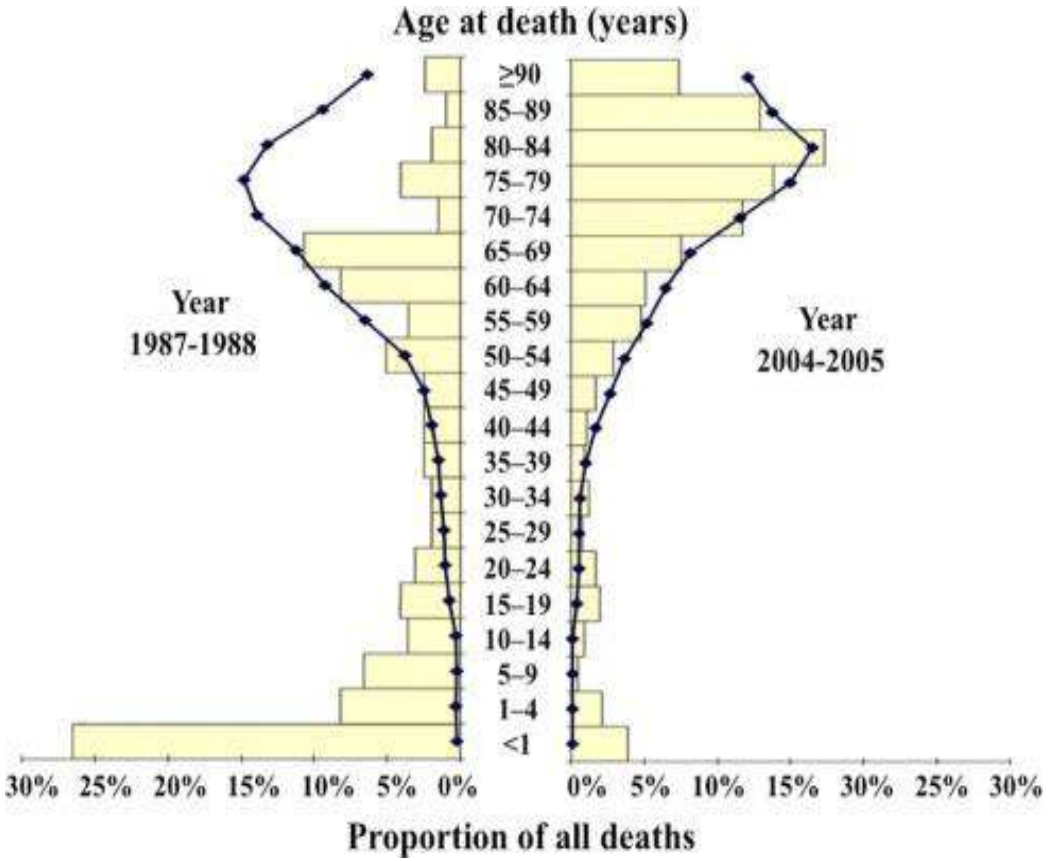
Congenital Heart Disease (CHD)

- 8-10/1000 live births
- ~ 90% survive till adulthood
- Adults outnumbered children x 3
- Issues - Morbidity & HRQOL



Khairy et al., 2009

AHA Scientific Statement

Cardiovascular Health: The Importance of Measuring Patient-Reported Health Status

A Scientific Statement From the American Heart Association

Table 1. Top Things to Know

- Improving cardiovascular health is a central goal of cardiovascular care and a specific aim of the American Heart Association's strategic goals; however, measures of cardiovascular health beyond mortality and morbidity outcomes have not been well specified.
- Patient-reported health status, which includes symptom burden, functional status, and HRQL, is an important measure of health.
- Validated patient health status surveys, including disease-specific instruments for patients with cardiovascular disease, allow for the quantification of this critical, patient-centered outcome.
- Cardiovascular patient health status surveys have been used successfully in clinical trials and other research studies to quantify treatment benefits with regard to symptoms, functional status, and HRQL; however, they remain underutilized.
- In addition to cardiovascular disease–specific factors contributing to worse patient health status (eg, amount of angina in coronary artery disease), other key cofactors must be recognized (eg, comorbid depression). There are also special considerations in the measurement of health status in cohorts such as the elderly.
- Patient-reported health status is an independent predictor of subsequent mortality, cardiovascular events, hospitalization, and costs of care. This has potential implications for risk adjustment and targeting of healthcare resources.
- Patient health status data have the potential to inform clinical decision making. In particular, such information can be important for shared decision making.
- Cardiovascular patient health status assessments can facilitate disease surveillance and quantify populations' health for entities such as accountable care organizations but have not yet been incorporated into population health/disease surveillance efforts. The integration of health status into these activities may enhance the patient-centeredness of care and better characterize the impact of healthcare delivery on patient health.
- Additional research is needed to better understand the determinants of patient health status, the effects of interventions on cardiovascular health, and the most effective strategies to incorporate cardiovascular patient health status measurement in clinical practice and disease surveillance.

HRQL indicates health-related quality of life.

Health Related Quality of Life

The prevalence of sexual dysfunction and its association with quality of life in adults with congenital heart disease

Alexandra Neiman BA [a, 1], Salil Ginde MD [b, 1], Michael G. Earing MD [c, 1], Peter J. Bartz MD [b, 1], Scott Cohen MD [c]

Quality of Life 20 and 30 Years After Surgery in Patients Operated on for Tetralogy of Fallot and for Atrial Septal Defect

Authors | Authors and affiliations

B.-M. Ternestedt, K. Wall, H. Oddsson, T. Riesenfeld, I. Groth, J. Schollin

Psychosocial Functioning and Quality of Life in Adults with Congen

Adrienne H. K

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activity lev

Annika Bay [a, b]

Engström [g, 1], Ph

Quality of life in adults with congenital heart disease

DATA FROM LOWER MIDDLE INCOME COUNTRY ???????

Illness perceptions of adults with congenital heart disease and their predictive value for quality of life two years later

Dounya Schoormans, Barbara JM Mulder, Joost P van Melle, more... Show all authors

15 Countries: Evaluating Country-Specific Characteristics

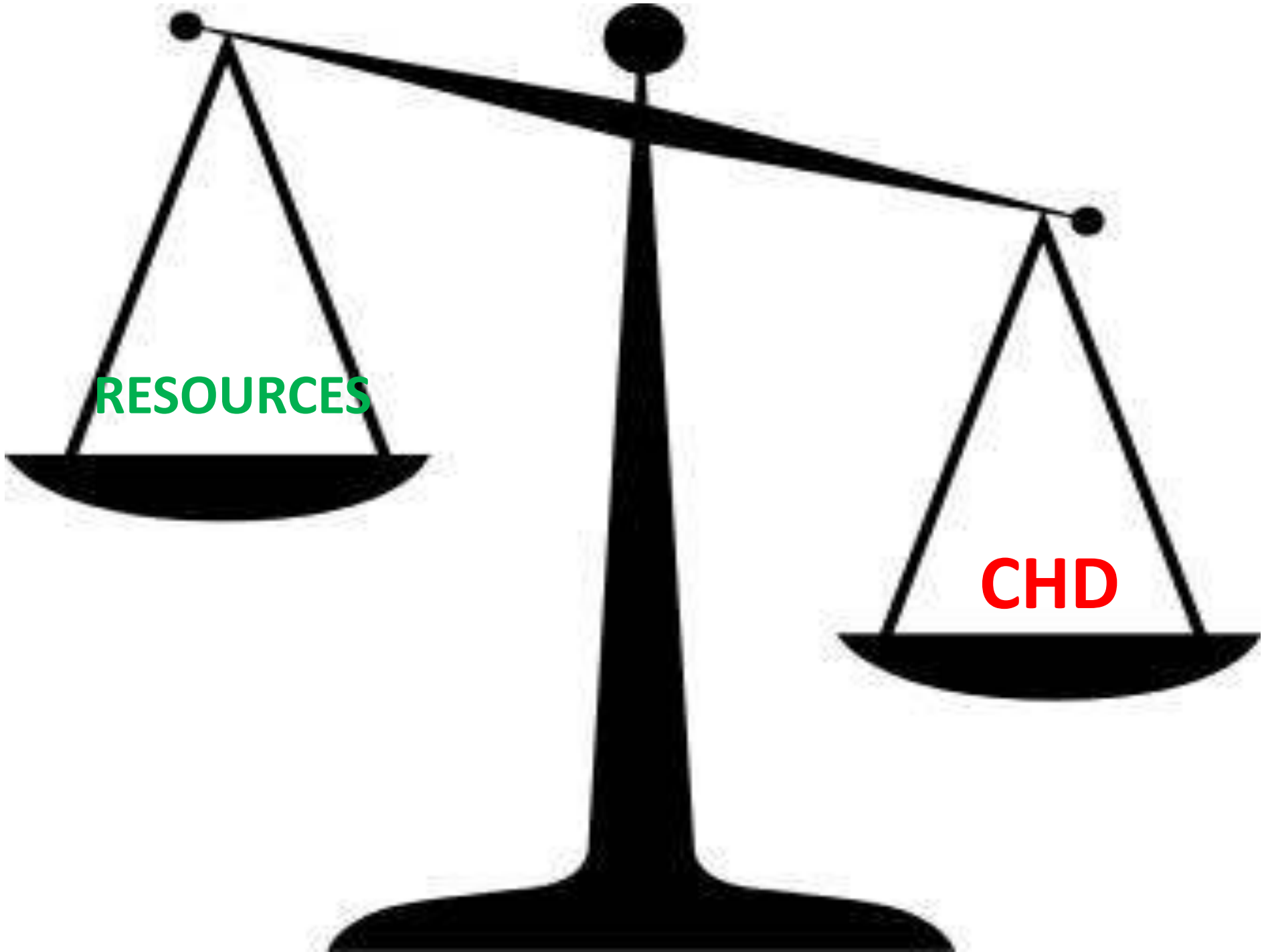
Silke Apers PhD [a], Adrienne H. Kovacs PhD [b], Koen Luyckx PhD [c], Corina Thomet MSc [d], Werner Budts MD, PhD [e], Junko Enomoto PhD [f], Maayke A. Sluman MD [g], Jou-Kou Wang MD, PhD [h], Jamie L. Jackson PhD [i], Paul Khairy MD, PhD [j], Stephen C. Cook MD [k], Shanthi Chidambarathanu MD [l], Luis Alday MD [m], Katrine Eriksen MSc [n], Mikael Dellborg MD, PhD [o, p], Malin Berghammer PhD [o], Eva Mattsson MD, PhD [q], Andrew S. Mackie MD [r] ... Philip Moons PhD [a, o]

Long-Term Outcome and Quality of Life in Adult Patients After the Fontan Operation

Annemien E. van den Bosch, MD, Jolien W. Roos-Hesselink, MD, Ron van Domburg, PhD, Ad J.J.C. Bogers, MD, PhD, Maarten L. Simoons, MD, PhD, and Folkert J. Meijboom, MD, PhD

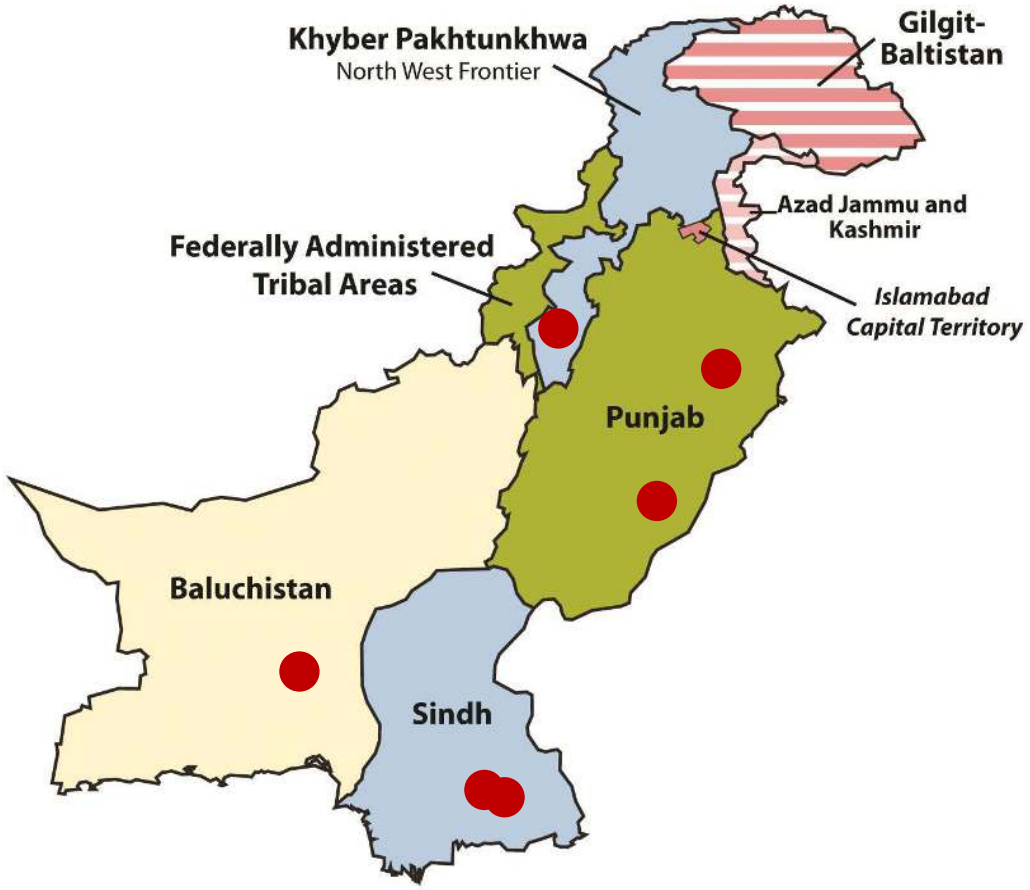
Illness perceptions in adult congenital heart disease: A multi-center international study.

Rassart J[1], Apers S[2], Kovacs AH[3], Moons P[4], Thomet C[5], Budts W[6], Enomoto J[7], Sluman MA[8], Wang JK[9], Jackson JL[10], Khairy P[11], Cook SC[12], Subramanyan R[13], Alday L[14], Eriksen K[15], Dellborg M[16], Berghammer M[17], Johansson B[18], Rempel GR[19], Menahem S[20], Caruana M[21], Veldtman G[22], Soufi A[23], Fernandes SM[24], White KS[25], Callus E[26], Kutty S[27], Luyckx K[2]; APPROACH-IS consortium and the International Society for Adult Congenital Heart Disease (ISACHD).


RESOURCES
CHD

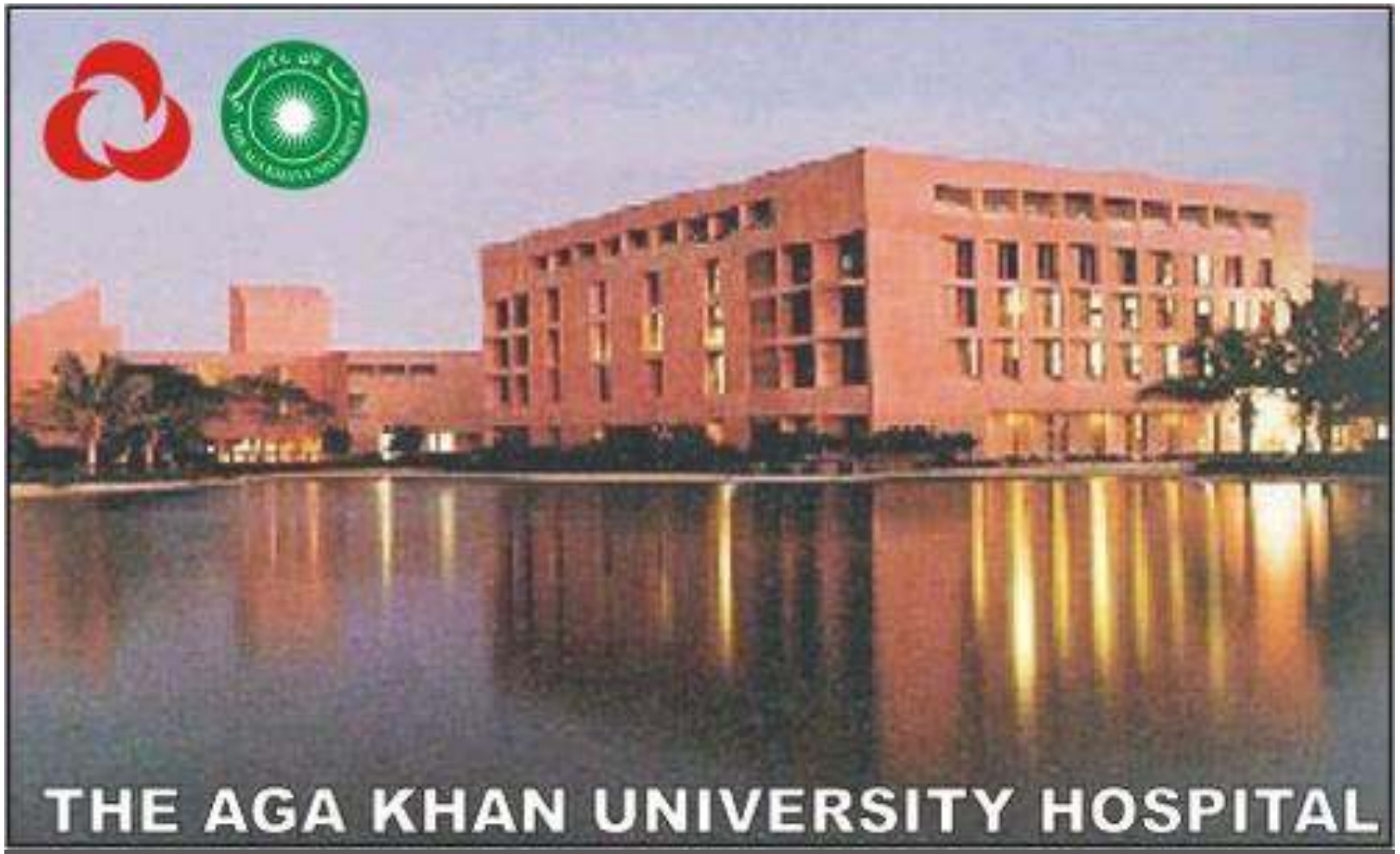
Pakistan- CHD Overview

	Approximation
Population	189 million
CHD Incidence	50,000/year
CHD Health care services	6 Hospitals
CHD Surgeries	3000/year
Pediatric Cardiac Surgeon	8
Pediatric Cardiologist	25



http://ppcsociety.org/

Study Setting



Study Objectives

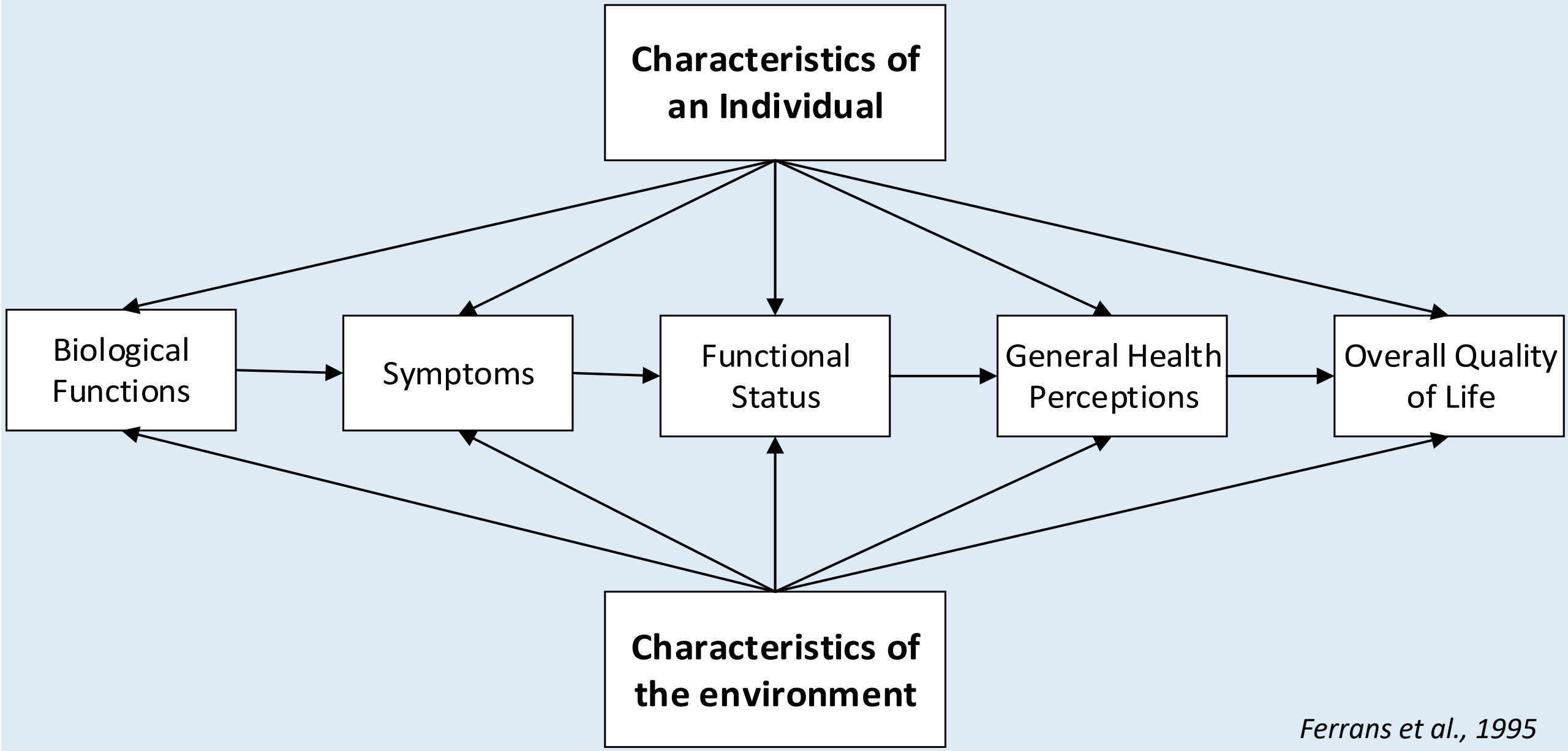
Primary Objective:

To determine HRQOL in CHD adults following surgery.

Secondary Objectives:

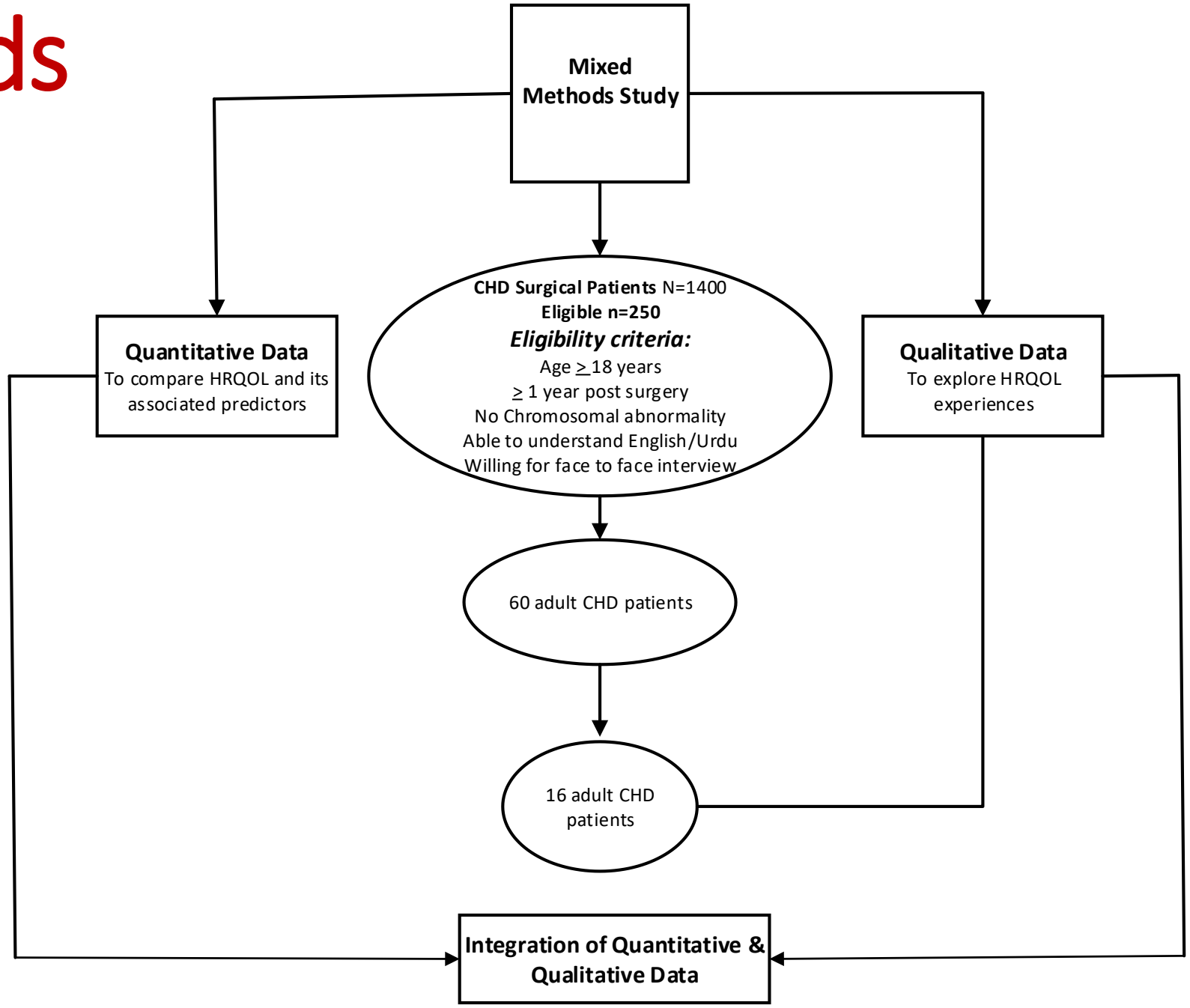
To understand the patient experiences of CHD after surgery

Revised Wilson and Cleary Model



Ferrans et al., 1995

Methods


Mixed Methods Study
CHD Surgical Patients N=1400
Eligible n=250
Eligibility criteria:
Age ≥ 18 years
≥ 1 year post surgery
No Chromosomal abnormality
Able to understand English/Urdu
Willing for face to face interview
Quantitative Data
To compare HRQOL and its associated predictors
Qualitative Data
To explore HRQOL experiences
60 adult CHD patients
16 adult CHD patients
Integration of Quantitative & Qualitative Data

Data Collection

Quantitative Data

- Socio Demographic Data
- Clinical & Surgical Data
- **PedsQL Core version 4.0**
- **PedsQL 4.0 Cognitive Questionnaire**
- **PedsQL 3.0 Cardiac Module**

Analysis:
Descriptive Analysis

Qualitative Data

- **Semi-structured, self-developed interview guide on everyday experiences of living with CHD**

Analysis:
Directed Content Analysis
(using Wilson Cleary model of HRQOL)

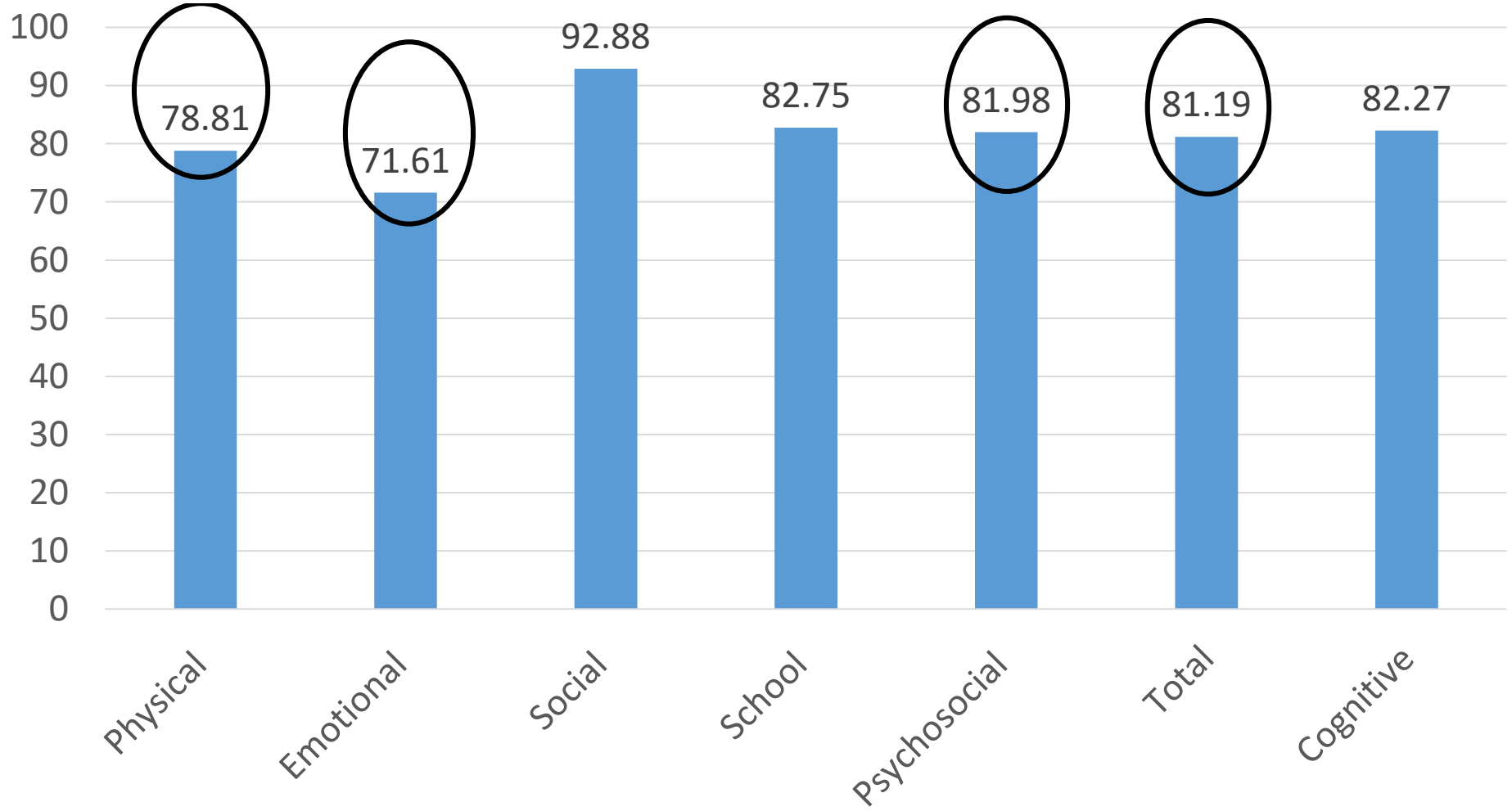
Participants Characteristics

	n	%age
Gender		
Male	30	50.8
Female	29	49.2
Age at Assessment (years) mean (SD)	29.66 ± 10.70	
Occupation		
Employed/Business	20	33
House Wife	19	32
Student	21	35
Family Income (Pakistani Rupees)		
Below poverty line LMIC	29	48
Above poverty line LMIC	31	52
Family Structure		
Nuclear	20	40
Extended	40	60
Martial Status		
Single	31	52.5
Married	28	47.45
Distance of cardiac facility from home (km) - Mean	77.82 ± 234.32 (1-1700)	

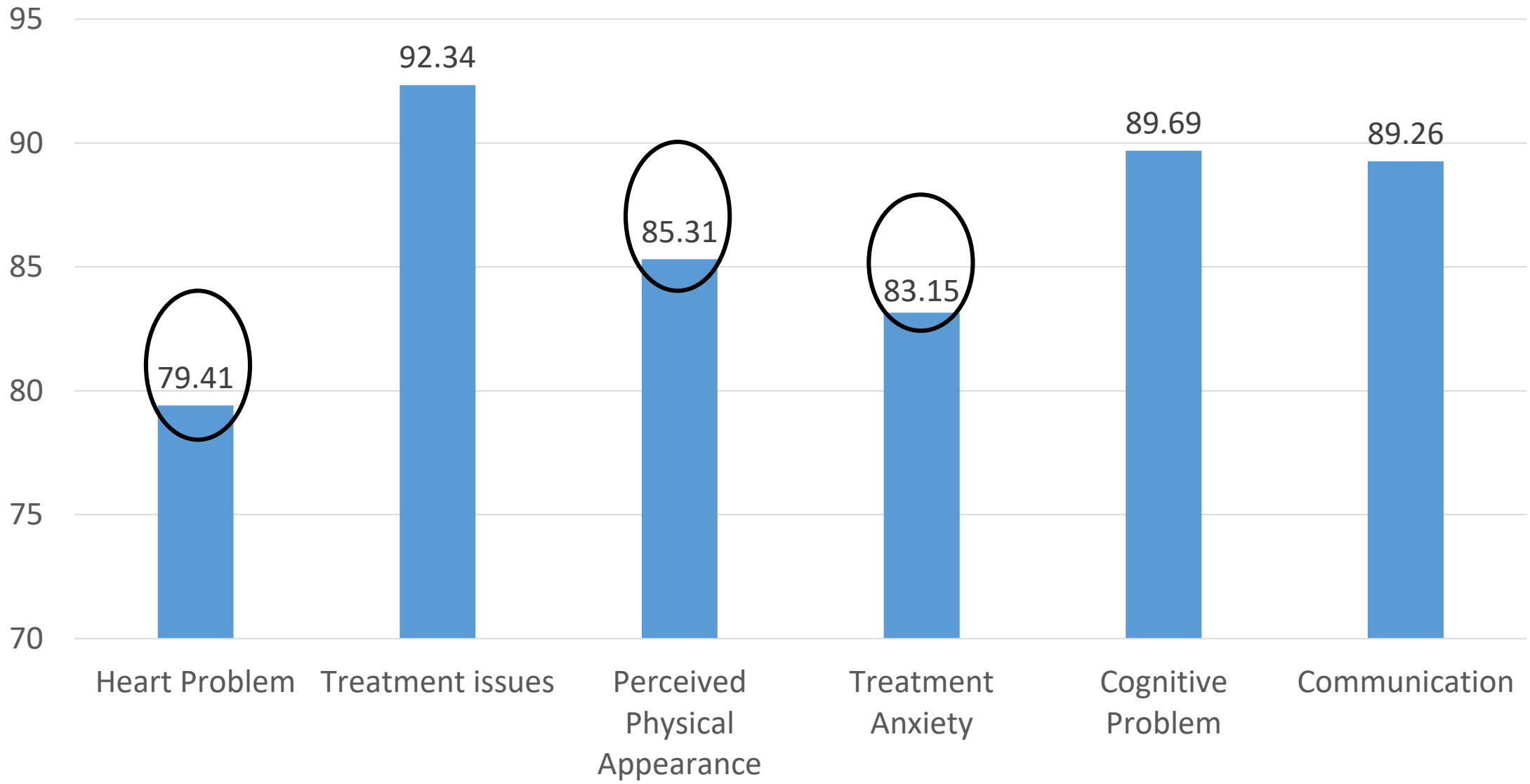
Participants Characteristics

	n	%age
CHD Severity		
Mild	16	29.6
Moderate	35	64.8
Complex	3	5.6
Number of Surgeries		
1	49	81
≥ 2	11	19
Cardiac Prognostic severity		
RACHS 1	16	27.1
RACHS 2	28	47.5
RACHS 3	15	25.4
Age at diagnosis (years) mean (SD)	14.34 ± 16.98	
Age at 1st surgery (years) mean (SD)	24.50 ± 12.66	
F up period since last surgery (years) mean (SD)	4.00 ± 1.82	
Cardiopulmonary Bypass time (mins) mean (SD)	126 ± 71.94	
NYHA		
I	49	82
II & above	11	18

General HRQOL in ACHD surgical patients



Cardiac HRQOL in ACHD surgical patients



Participants' Perceptions

"I try my level best to complete tasks on time but I am always late… my friends complete their work [house chores] in 3-4 hours… but my entire day is spent in completing house chores so I'm never free "

(39 years female, TOF repair)

"… when I used to sit in a public transport like bus, go to market or some crowded place… my heart would beat faster… and I was very scared… I was sweating… I could not go anywhere alone"

(30 years male, Coarctation of aorta)

"If it would have happened before marriage, I would have been more concerned and so would my family. I was still concerned about operation scars I have, like 'What will my husband or my in laws think about it?" but thank God, my husband is okay with it."

(28 years female, TOF correction)

Society's Perspective

"I need to get well and I do not want to go for more surgery… I am the eldest son, my father is looking after the entire business… I have an unmarried sister as well… I need to remain fit in future to fulfil all my responsibilities as a son and elder brother."

(32 years male, AVR, VSD)

"My cousin told me that this disease is due to **your sins**, but I don't feel that way. I think God can give disease to anyone."

(25 yrs male, TOF)

"…. People think negatively about medicine, that I am **not normal**… I did not feel comfortable taking medicine in front of them so I skipped my medicine…"

(18 yrs female, AVR, VSD repair)

Participants' Concerns

Health

Education

Finance

Re-operation

Extended Family

Marriage

Conception

Participants Concerns

"The most important thing is health. If your health is good, you can take care of your kids and family… I cannot take care of myself, so how I can care for my kids and family? This makes me worried" (24 yrs male, AVR, TOF)

"I had to undergo a thorough check-up for my job. I was bit scared… as I didn't want to be refused on the basis of my cardiac surgery… They inquired what medicine I was on… they were basically worried about contagious diseases …" (22 yrs female, ASD, VSD)

"When I get marriage proposals, they liked my appearance, my personality, my family's prestige in the society… But when… my father would tell them about my surgery… they would reject me because of my heart surgery and secondly they fear I will not be able to conceive and I'm not medically fit. But they would come up with silly excuses…"

(26 years female with AVR, VSD)

Conclusion

HRQOL was lower in CHD adult surgical patients in both general and cardiac specific HRQOL in a LMIC, Pakistan

ACHD patients need support particularly in emotional, physical functioning, symptoms and anxiety related to ACHD treatment

Implications

HRQOL should be part of regular clinical screening in CHD

Solutions need to address the HRQOL and lifelong concerns of patients

Longitudinal multi-central studies on HRQOL in CHD need to be conducted in Pakistan/LMIC

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