

Quality of life of caregivers with children having congenital heart disease awaiting cardiac surgery at the Lady Ridgeway Hospital for Children, Colombo, Sri Lanka

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Abstract

Introduction: Congenital heart disease (CHD) has an accepted estimated prevalence of around 8-12/1000 live births

Objectives: To determine the level of quality of life (QOL) of primary caregivers whose children with CHD are attending cardiology clinics in Lady Ridgeway Hospital (LRH), Colombo, awaiting cardiac surgery.

Method: This study was carried out as an institution-based descriptive cross-sectional study, of 422 caregivers, through consecutive convenient sampling method over a two month period at the cardiology unit of Lady Ridgeway Hospital. An interviewer administered questionnaire was utilized to obtain data and the QOL was assessed by WHOQOL-BREF questionnaire which was validated in Sri Lanka and consists of 26 questions. WHOQOL-BREF is an abbreviated generic QOL scale developed through the World Health Organization. Question one is the individual's overall perception of QOL, and question two is individual's overall perception of health. Rest of the 24 questions are in four domains, physical health, psychological health, social relationship and environmental relationship. Data extraction sheet was used to get clinic records. Univariate analysis and regression were done to detect association.

Results: Of the caregivers 89.3% were mothers, 51% were in the 30 to 39-year age group, and 75% were unemployed. Overall perception of QOL and

overall perception of their health had means of 2.48 (SD 0.66) and 2.48 (SD 0.67) respectively. The highest mean score was recorded in social relationship domain and was 57.15 (SD 12.87), whilst the lowest mean score was recorded in psychological domain and was 39.38 (SD 11.93). Except for social relationship domain, all other domain scores were less than 50% of QOL.

Conclusions: Caregivers of children with CHD attending cardiology clinics in LRH, Colombo and awaiting cardiac surgery are experiencing a low QOL. The QOL was associated with age of the caregiver, educational level, marital status, number of children, income, type of heart disease, and postponement of surgery. QOL had no significant association with gender, religion, employment status or presence of co-morbidities.

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(Key words: Quality of life, primary caregivers, children with congenital heart disease awaiting cardiac surgery)

Introduction

Congenital heart disease (CHD) has an accepted estimated prevalence around 8-12/1000 live births¹. Common severe congenital anomalies are heart defects, neural tube defects and Down syndrome². From 1960-1994 in the USA, birth defect specific infant mortality decreased by 53% but congenital anomalies still remained the leading cause of infant deaths³. Unlike in the West, CHD is not familiar territory for researchers in Sri Lanka. Therefore, it is extremely difficult to obtain the complete Sri Lankan scenario of CHD⁴. Other leading causes of death for children in the age group 0 to 4 years are congenital malformations, deformations and chromosomal abnormalities which together account for 24% of total deaths in that age group⁵. As CHD is the commonest congenital anomaly, it contributes significantly to neonatal and infant mortality in Sri Lanka⁴. The limited data available show that numbers in Sri Lanka are compatible with world prevalence of CHD⁴. According to the WHO definition, quality of life (QOL) is an individual's perception of his position in life, in the context of the culture and value system, in which he lives and in relation to his goals, expectations, standards, and concerns⁶. QOL is also an essential

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outcome measure in health economic evaluations, which are fundamental in allocating health care resources⁷.

Lady Ridgeway Hospital (LRH) is the only tertiary care referral centre for children with CHD in Sri Lanka. A considerable number of children need surgical or catheter based treatment within first year of life. Annually, more than thousand cardiac surgeries and cardiac catheterizations are done in LRH, which is about 55% of the annual need for cardiac intervention. There are also very few government and private hospitals equipped to perform such a procedure in Sri Lanka⁸. According to hospital data, over 3000 children are born with CHD in Sri Lanka per year. Of this number, the hospital can only treat 1700 children annually. Over 40% of these children do not have appropriate access to early intervention and are compelled to await their turn⁹. Around 1000 children with CHD are waitlisted for treatment annually, due to the hospital's limited capacity. Most of them have to wait for months or years, due to resource constraints. With the passage of time, chances of recovery of these children lessen and some may even die of the illness before their turn for surgery⁹. Over 90% of these CHDs could be cured with timely, and proper treatment. Even though the cost of each surgery is high (around RS. 100,000) for the medicine and consumables when these children are treated on time, they become normal and productive citizens. If they do not receive timely and proper treatment these children are a huge burden on their families and this will affect their QOL further⁸. There are not enough studies published in Sri Lanka on children with CHD and these are not sufficient to provide a satisfactory image of the burden to their families. Therefore, this study will explore an important territory of the problems faced by caregivers of children with CHDs awaiting surgery in Sri Lankan context.

Objectives

To determine the level of quality of life (QOL) of primary caregivers whose children with CHD are attending cardiology clinics in LRH, Colombo, awaiting cardiac surgery.

The *specific objectives* are to:

- To determine the level of QOL of the primary caregivers whose children with CHD are attending cardiology clinics in LRH, Colombo, awaiting cardiac surgery.
- To describe the factors associated with the QOL of the primary caregivers.

Method

A cross sectional descriptive study was carried out in the cardiology clinics at LRH, Colombo. Data were collected from August 2017 to September

2017. Study population comprised primary caregivers of children with diagnosed CHD followed up in the cardiology clinics at LRH for at least six months awaiting cardiac surgery. Primary caregivers who had siblings with chronic illnesses, primary caregivers who had chronic illnesses and caregivers accompanying the patient on the data collection day who were not the regular caregiver, were excluded to reduce selection bias.

The sample size¹⁰ was 426. Convenient consecutive sampling technique was used. A structured pretested interviewer administered questionnaire, inclusive of WHO, QOL-BREFF Tool, which has been translated to the Sinhala language by the Field Centre for WHOQOL, University of Ruhuna¹¹, and the data extraction sheet were used. BREFF tool validated in Sri Lanka showed good convergent and discriminant validity¹². It consists of 26 questions. Question one targeted an individual's overall perception of QOL and his or her life, and question two targeted an individual's overall perception of his/her health. The remaining 24 questions were categorized into four domains, namely, physical health, psychological health, social relationship, and environmental relationship¹³. To minimize inter-observer variations only one pre-intern medical officer was used as a data collector in addition to the principal investigator.

The data processing and analysis were done by the principal investigator using the Statistical Package of Social Sciences (SPSS) version 21. Data related to QOL were also entered, according to instructions and guidelines provided by the WHO QOL group to obtain total domain scores. Data analysis for inferential statistical to determine the association between socio-economic factors and child factors with levels of the four domains of QOL were considered as dependent variables, while the associated factors were considered as independent variables. Normal distribution was confirmed by normality test and Q-Q plots for scores of the tool. Student t-test was used for the bivariate analysis. A "p" value of less than 0.05 was considered as statistically significant. Regression analysis was used to exclude the confounders.

Ethical clearance to conduct the study was obtained from Ethics Review Committee of the Post Graduate Institute of Medicine. Simultaneously approval was obtained from Ethics Review Committee of LRH.

Results

Response rate was 99%. Sample comprised 422 caregivers of children with diagnosed CHD awaiting cardiac surgery. The demographic characteristics of caregivers are shown in Table 1.

Table 1: Demographic characteristics of caregivers (n=422)

Characteristic	Number (%)	Characteristic	Number (%)
<i>Gender</i> Female Male	382 (90.5) 40 (09.5)	<i>Age group (years)</i> <20	04 (0.9)
		20-29	117 (27.7)
		30-39	217 (51.4)
		40-49	77 (18.2)
		50-59	07 (01.7)
<i>Primary caregiver</i> Mother Father Others	377 (89.0) 39 (09.3) 06 (01.7)	<i>Educational level</i> No formal schooling	02 (0.4)
		Primary (grades 1-5)	26 (06.1)
		Grades 6-11	147 (34.8)
		Passed GCE O/L	107 (25.4)
		Follow GCE A/L	77 (18.2)
		Passed GCE A/L	36 (08.5)
		Vocational training	09 (02.3)
		Higher education	18 (04.2)
<i>Ethnicity</i> Sinhalese Others	342 (81.0) 80 (19.0)	<i>Number of children</i> One	114 (27.0)
		Two	176 (41.7)
		Three	110 (26.1)
		Four	18 (04.3)
		More than four	04 (0.9)
<i>Marital status</i> Married Widow Separated Divorced Unmarried	410 (97.2) 0 08 (01.9) 04 (0.9) 0	<i>Employment status</i> Employed	105 (24.9)
		Unemployed	317 (75.1)
<i>Religion</i> Buddhism Others	320 (75.8) 102 (24.2)	<i>Income (Rupees)</i> <10,000	22 (05.2)
		10,000-20,000	115 (27.3)
		20,001-30,000	110 (26.1)
		30,001-50,000	125 (29.6)
		>50,000	50 (11.8)

Majority of primary caregivers were mothers in the age group 30 to 39 years. Of the primary caregivers 59% had an income less than Rs. 30,000 and 75% were unemployed. The surgery date was given only in 131 (31%) cases so that 69% were in the waiting list without being given the date of surgery.

Furthermore, surgery was postponed in 124 (23.4%) cases.

The distribution of facet and domain scores of patients in relation to QOL is shown in Table 2.

Table 2: Distribution of facet and domain scores of patients in relation to the quality of life

	Mean	SD	SE of Mean	Minimum	Maximum	Range
<i>Facet</i>						
Q1 - Overall QOL	2.48	0.66	0.03	1	4	3
Q2 - Health status	2.48	0.66	0.03	1	4	3
<i>Domain</i>						
Physical health	39.52	10.78	0.08	13	69	56
Psychological	39.38	11.93	0.06	6	69	63
Social relationship	57.15	12.87	0.1	6	75	69
Environmental	43.92	8.75	0.07	19	69	50

SD= standard deviation SE of mean = Standard error of mean difference

The highest mean score of QOL, which was 57.15, was recorded in the social relationship domain and the lowest, which was 39.38, was recorded in the psychological domain. Excepting social

relationship domain, all other domain scores were less than 50% of QOL (Table 2).

The association of sociodemographic factors and QOL is shown in Table 3.

Table 3: Association of sociodemographic factors and quality of life (n=422)

Variable	n	Physical health Mean (SD)	t p	Psychological health Mean (SD)	t p	Social health Mean (SD)	t p	Environmental health Mean (SD)	t p
Married	410	39.3 (10.7)	1.589	40.9 (10.4)	5.032	57.4 (12.7)	2.876	44.2 (08.5)	2.633
Unmarried	12	34.5 (11.1)	0.113	34.9 (10.6)	<0.001	46.9 (18.3)	0.005	35.0 (11.5)	<0.001
Education<11 yrs.	175	39.6 (10.4)	0.158	38.7 (11.8)	0.985	55.5 (12.4)	2.26	42.5 (09.5)	2.91
Education>11 yrs.	247	39.4 (11.0)	0.875	39.8 (12.0)	0.325	58.3 (13.1)	0.024	45.0 (07.9)	0.004
Employed	105	40.5 (10.1)	1.1	39.1 (12.9)	0.022	56.0 (12.8)	0.822	43.8 (08.3)	0.602
Unemployed	317	39.1 (10.9)	0.265	39.4 (11.6)	0.824	57.3 (12.9)	0.549	43.9 (08.9)	0.827
Income<30,000	247	39.4 (10.9)	0.277	39.2 (12.2)	0.331	56.3 (13.5)	1.598	43.1 (09.1)	2.339
Income >30,000	175	39.7 (10.4)	0.782	39.6 (11.5)	0.74	58.3 (11.7)	0.111	45.1 (08.1)	0.02
No. of children<2	290	39.1 (11.1)	0.984	39.6 (11.8)	0.508	58.0 (12.4)	2.135	43.9 (08.7)	0.836
No. of children>2	132	40.2 (10.1)	0.327	38.9 (12.8)	0.612	55.2 (13.5)	0.033	43.9 (08.8)	0.952
Male	40	41.2 (10.7)	1.024	37.4 (10.4)	0.074	54.1 (16.9)	1.57	44.1 (06.9)	1.31
Female	382	39.3 (10.8)	0.307	39.6 (11.8)	0.284	57.4 (12.5)	0.053	44.1 (08.9)	0.191
Age <30 yrs.	121	38.4 (10.4)	1.52	35.6 (14.0)	3.456	56.1 (13.2)	2.426	44.2 (08.5)	0.593
Age >30yrs	301	38.1 (10.7)	0.129	40.0 (10.7)	<0.001	59.3 (11.9)	0.016	43.9 (08.9)	0.683

Demographic data were amalgamated in two categories for the analysis. As shown in table 3, caregivers who were unmarried/ divorced or separated had low QOL and that was statistically significant in psychological, environmental (p=0.005) and social relationship domain (p<0.001). The mean QOL scores of caregivers who had education less than year 11, had a low

QOL in all domains, except physical domain, and this association was statistically significant in social relationship (p=0.024), and environmental health domain (p=0.004). Caregivers whose income level was less than RS 30,000 were low in mean score of QOL, in all four domains. This association was statistically significant in environmental domain of the QOL (p<0.002) (Table 3).

Table 4: Association of other factors and quality of life

Variable	n	Physical health Mean (SD)	t p	Psychological health Mean (SD)	t p	Social health Mean (SD)	t p	Environmental health Mean (SD)	t p
Surgery date given	131	38.8 (11.5)	0.919	35.1 (13.1)	5.047	57.2 (13.5)	0.085	44.1 (09.4)	2.14
Surgery date not given	291	39.3 (10.3)	0.359	41.0 (10.8)	<0.001	57.1 (12.3)	0.935	44.5 (08.9)	0.032
Surgery not postponed	298	39.8 (10.2)	0.867	41.2 (10.7)	5.076	57.1 (12.5)	0.037	44.4 (08.3)	0.013
Surgery postponed	124	38.8 (12.1)	0.386	34.9 (10.6)	<0.001	57.0 (13.8)	0.97	42.0 (09.6)	0.074
Acyanotic heart disease	317	39.5 (11.0)	0.079	40.5 (10.8)	3.565	57.7 (12.2)	0.153	43.9 (09.1)	0.064
Cyanotic heart disease	105	39.5 (11.0)	0.937	35.8 (14.1)	<0.001	55.4 (14.5)	0.122	43.9 (07.8)	0.949

As shown in table 4, caregivers whose children's surgery dates were given had low mean QOL scores in all four domains. Association was statistically significant in psychological domain of the QOL (p <0.001) as well as the environmental domain of the QOL (p= 0.032). Caregivers whose children's surgery was postponed had low mean QOL scores in all domains, which was statistically significant in psychological domain of the QOL (p<0.001). Caregivers of children with cyanotic heart disease had poor QOL in all four domains and that association was statistically significant in psychological domain of QOL (P<0.001) (Table 4).

However, the associations of psychological domain of the QOL were with religion and type of heart disease. Postponement of the surgery was judged to be non-significant following the multivariate analysis. On the other hand, surgery date given, marital status (unmarried/divorced, and separated) and age less than 30 years correlated with psychological domain of the health related QOL.

Multiple linear regression analysis was performed to determine the associations between sociodemographic and other factors of caregivers and child level predictors with each of the domains, in a multivariate model. For each of the four domains separate analyses were conducted to determine correlates (Table 5).

In the social relationship domain, correlates of QOL were unmarried status (p<0.005), and age less than 30 years (p<0.009) and educational level less than year 11 (p<0.025). Nevertheless, number of children and religion, which were significant in the bivariate analysis were found to be non-significant.

The bivariate analysis of the psychological domain revealed statistically significant associations for all factors considered for the multivariate analysis.

Being unmarried and education level less than year 11, correlates with QOL pertaining to environmental domain in the multivariate analysis.

There was no association found with physical health domain of the QOL as per binary variable.

Table 5: Multivariate analysis

Factor	p-value	Unadjusted beta	95% confidence interval	
			Lower	Upper
Psychological domain				
Surgery date given	0.006	3.001	0.882	5.120
Marital status	0.031	-6.449	12.31	0.558
Age less than 30 years	0.051	-2.06	4.128	0.008
Postponement of surgery	0.666	1.227	4.365	6.819
Social domain				
Marital status (unmarried, separated)	0.005	2.817	17.647	3.153
Education less than 11 years	0.025	-2.817	5.275	0.360
Age less than 30 years	0.009	3.403	0.843	5.963
Number of children more than two	0.332	-1.432	4.341	1.470
Environmental domain				
Marital status	0.001	-8.54	4.119	0.335
Education less than 11 years	0.005	2.412	4.092	0.732
Surgery date given	0.076	1.597	0.170	3.364
Income less than Rupees 30,000	0.237	-1.031	2.742	0.680

Discussion

As there were no published studies in Sri Lanka on QOL of a caregiver of children having CHD, this study will provide baseline information for future studies. The highest mean, namely 57.15, was recorded in the physical health domain. The mean score of the psychological domain was the lowest namely 39.38. Except for social relationship domain, all other domain values were less than 50%. This finding tallies with a study done in Taiwan^{14,15}. Mean QOL scores were lower in unmarried/widowed caregivers in all four domains. This association was statistically significant in mean QOL scores in social relationship ($p=0.005$), psychological domain and environmental domains categories ($p < 0.001$). This finding was similar to the study done in Iraq¹⁵.

Caregivers with income less than Rupees 30,000 had low QOL in all domains and this association was statistically significant in environmental domain ($p<0.02$). This finding was consistent with study findings of Iraq¹⁵ and cross sectional study was conducted in Alexandria, Egypt in the two main hospitals that treat children with heart disease¹⁶. Caregivers whose children with cyanotic heart disease were poor QOL in all four domains and that association is statistically significant in psychological domain of QOL ($p<0.001$). Similar results were presented by a study in Iraq¹⁵ and Alexandria, Egypt¹⁶.

Caregivers whose children got the surgery dates had low mean QOL scores in all domains. This association was statistically significant at psychological domain of the QOL ($p<0.001$) as well as the environmental domain of the QOL ($p<0.032$). This finding may be due to parents getting stressed out after getting a surgery date as their child is undergoing a major surgery.

Caregivers whose children had postponement of date of surgery had low mean QOL score values. This association was statistically significant at psychological domain of the QOL ($p<0.001$).

This study was hospital based due to feasibility issues as data were collected during a two month period which consisted of an interviewer administered questionnaire, discussion with caregivers and advice and clarifications which were time consuming. The study was limited to caregivers of children who presented to the hospital for care. Those who are not been followed up in clinics regularly and those who are taking treatment in private sector were not represented in this study.

Conclusions

Caregivers of children with CHD attending cardiology clinics in LRH, Colombo and awaiting cardiac surgery are experiencing a low QOL. The QOL was associated with age of the caregiver, educational level, marital status, number of children, income, type of heart disease, and postponement of surgery. QOL had no significant association with gender, religion, employment status or presence of co-morbidities.

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