Research Article

Health Related Quality of Life of Rheumatic Heart Disease Patients in Alexandria: An Intervention Approach

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ABSTRACT

Background: Rheumatic heart disease (RHD) is a chronic illness resulting from one or more attacks of acute rheumatic fever and characterized by permanent heart valve damage. RHD affects the health related quality of life (HRQOL) of patients.
Objective: to describe the HRQOL of RHD cases in Alexandria.
Methods: A retrospective descriptive study and an intervention (one group pretest post-test) approach were used to study RHD and its effect on the HRQOL of the patients registered at the RHD unit in the Main University Hospital and Heart Clinic of El-Shatby University Children's Hospital in Alexandria. Data were collected using a pre-designed structured interviewing questionnaire and the generic form of HRQOL questionnaire (SF-36). An intervention program was designed based on the results and perception was reassessed using the same study tools.
Results: Regarding the mean scores of HRQOL subscales of RHD cases, scores related to physical components and general health were lower compared to the emotional and social ones. Studying the effect of the personal characteristics of the RHD cases on HRQOL, one-way MANOVA indicated a significant impact of age, diagnosis, complications, attacks, period between treatment and injection. The general perception score was 87.505 ±6.935 and 76.477 ±11.575 pre and post intervention with a highly significant difference. After intervention, RHD patients were about seven and half times more likely to have good level of perception compared to RHD cases before intervention.
Conclusion: RHD cases of 30 years and above were found to be statistically associated with poorer HRQOL in all domains except the role limitations due to emotional problems. RHD with valve affection had significant influence on the worst HRQOL in social functioning only. RHD cases receiving treatments every month had a significant poorer HRQOL in all domains in comparison with other periods of treatment. The intervention program had a significant effect on the general perception score among RHD patients.

Keywords: *Acute rheumatic fever, HRQOL, RHD, SF-36 questionnaire*

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INTRODUCTION

Rheumatic heart disease (RHD) is the permanent heart valve damage resulting from one or more attacks of acute rheumatic fever (ARF). ARF and RHD predominantly affect children, adolescents, and young adults, and are important causes of premature mortality.(1) Rheumatic heart disease requires long-term prophylactic treatment, including painful administration of intramuscular medication, which can result in frequent psychological disorders and treatment dropout. Another factor that contributes to deterioration of

the patient's quality of life is the presence of cardiopathies, which may cause functional and psychological limitations.[2]

Health related quality of life (HRQOL) refers to perceived physical and mental health over time.[3] HRQOL can be measured by different types of instruments namely, global, generic, condition specific, and utility measures. Generic measures include different types such as Nottingham Health Profile, Sickness Impact Profile, Short form -36 (SF-36), and many other forms.[4]

Health related quality of life domains include functional status (e.g. whether patient is able to manage a household, or dress independently), mental health or emotional well-being (e.g. depressive symptoms, positive affect), social engagement (e.g. involvement with others, engagement in activities), and symptom states (e.g. pain, fatigue).[5]

The current study was carried out to describe the HRQOL of RHD cases in Alexandria and to identify the most important factors that could affect it.

METHODS

A retrospective descriptive study and an intervention (one group pretest post-test) approach were used to study RHD and its effect on the HRQOL of the patients. The study was conducted among all patients with RHD registered at the RHD unit in the Main University Hospital and Heart Clinic of El-Shatby University Children's Hospital in Alexandria. Two hundred patients were included in the study. The intervention study was applied for patients whose perception towards disease was incoherent with their disease severity as assessed clinically and by echocardiography.

Different tools were used for data collection. A pre-designed structured interviewing questionnaire was used to collect data on demographic characteristics (age, sex, residence, and educational level), and socio-economic status (educational level of parents, family size, and crowding index). Other data included heart disease related data (diagnosis, date of diagnosis, and investigations done, severity of the disease, type of the treatment, treatment intervals, regularity in the treatment, causes of stoppage of treatment, the presence of complications and its types, presence of sore throat, recurrence of cardiac attacks and the causes of recurrence, previous admission to the hospital, times of admission, cause and days of hospitalization, effect of disease on patient's work and presence of other diseases) and presence of RHD among family members.

The (SF-36), the generic form of HRQOL questionnaire was also used to describe the HRQOL of RHD patients. Each SF-36 scale was scored using norm-based methods that standardize the scores to a mean of 50 and a standard deviation (SD) of 10, yielding score values of 0 to100, with higher scores indicative of better health.

Patients' files were reviewed to detect the onset of the disease, the prophylaxis used, the presence of complications, and the recurrence of attacks. The results of clinical examination and Color Doppler were reviewed to assess the current medical condition of the patients.

An intervention program was used. It was designed according to the results obtained from the study. Pretest and post-test were applied for patients whose perception towards disease was incoherent with their disease severity as assessed clinically and by echocardiography. They amounted to 50 patients. Three months after the end of the program, perception was reassessed using the same study tools.

The program consisted of three sessions which were held in the RHD unit of Alexandria Main University Hospital and lasted for a period of 3 months. During the program, health education of the patients and their families was done. Lectures and group discussions were used and educational material was provided. The main topics covered were the nature of the disease, its modes of transmission, its risk factors and the prevention and control.

Data were entered and coded using the Statistical Package for Social Sciences (SPSS version 16). General linear model - Multivariate analysis of variance (GLM -MANOVA) was used to explore the impact of the socio-demographic, medical, social and psychological aspects of the patient and family related factors on QOL of RHD patients and to compare SF-36 scores between domains. Significant statistics were followed by post hoc analyses to determine which subscale was showing group differences, and which specific groups were significantly different from one another.

Ethical considerations:

The study was approved by the Ethics Committee of the High Institute of Public Health. An informed consent was obtained from each patient who agreed to participate in the study after explanation of the

purpose of research. Confidentiality of information, and anonymity were guaranteed and maintained.

RESULTS

The socio-demographic characteristics of RHD patients are shown in table 1. It appears from the table that the mean age of patients was 27.39±15.2 years. About two thirds of the cases (64.5%) were females. Regarding education, 44% of cases were illiterate or just read and write. Those with primary or preparatory school education constituted 41% while those with secondary or higher education constituted 15% only. It was found that 40% of RHD cases were below the age of work. Among those in the working age, 69.2% were not working and 30.8% were working. Sixty percent of cases were living in urban areas while the rest (40%) were living in rural areas. The mean family size and crowding index were 6.06 ± 2.944 and1.92 ± 1.018 respectively.

Table 1: Distribution of studied RHD cases according to their socio-demographic characteristics, Alexandria, Egypt, 2012

Sociodemographic characteristics	No. (n=200)	%
Age (Mean±SD) 27.39 ± 15.21		
Gender		
Male	71	35.5
Female	129	64.5
Level of education		
Illiterate andread and write	88	44
Primary andpreparatory	82	41
Secondary andhigher	30	15
Working status(n=120)[a]		
Not working	83	69.2
Working	37	30.8
Residence		
Urban	120	60
Rural	80	40
Family size (Mean±SD) 6.06 ± 2.944		
Crowding index (Mean ±SD) 1.92 ± 1.018		

[a]80 patients were below the age of work

It appears from table 2 that about three quarters of cases (71.5%) were suffering from moderate degree RHD. Those with mild and severe degree RHD were 15.5% and 13% respectively. About one third of cases (33.5%) were suffering from different types of complications. Nearly three quarters of cases (72.5%) were receiving their treatment every two weeks, about one quarter once every month and 3.5% every three weeks. Regarding regularity of treatment, nearly, half of the cases (48.5%) were always receiving their treatment regularly, 15.5% were sometimes on regular treatment and 36% received the treatment irregularly.

Regarding, the mean scores of HRQOL domains of RHD cases, table 3 shows that scores related to physical components and general health were lower compared to the emotional and social ones. Studying the effects of the demographic characteristics of RHD cases on HRQOL, one-way MANOVA, table 4 indicated a significant impact of age (F= 8.510, p= 0.000), diagnosis (F= 1.395, p = 0.007), complications (F= 2.654, p= 0.013), attacks (F= 1.773, p= 0.042), period between treatments (F= 3.018, p= 0.000) and injection (F= 3.057, p= 0.005). The table also presented Eta squared which describes the proportion of total variability attributable to a factor and Wilks' Lambda that measures the percent of variance in the dependent variables that is not explained by differences in the level of the independent variable. Given the significance of the overall test, the univariate main effects were examined, table 5. Significant univariate main effects for age were statistically associated with poor HRQOL in all domains except the role limitations due to emotional problems and emotional well-being. Diagnosis and complications had a significant main effect on social functioning only (F= 2.533, p=0.002 and F= 10.000,

p=0.001 respectively). Notably, attacks had a significant impact on emotional well-being (F= 5.588, *p*= 0.004) and social functioning (F= 7.087, *p*= 0.001). Injections had a poor HRQOL on general health (F= 10.511, *p*= 0.001), physical functioning (F= 11.420, *p*= 0.001), role limitations due to physical health problems (F= 12.347, *p*=0.001), energy/fatigue (7.713, *p*= 0.006) and social functioning (F= 11.937, *p*= 0.001). The period between treatments had a significant effect on all domains except general health.

Table 2: Distribution of studied RHD cases according to their clinical characteristics and treatment, Alexandria, Egypt, 2012

Clinical characteristics and treatment	No. (n=200)	%
Severity of the disease		
Mild	31	15.5
Moderate	143	71.5
Severe	26	13
Presence of associated Complications		
No	133	66.5
Yes	67	33.5
Treatment interval		
Every two weeks	145	72.5
Every three weeks	7	3.5
Every one month	48	24
Regularity of treatment		
Always regular	97	48.5
Sometimes regular	31	15.5
Irregular	72	36

Table 3: Means for the SF-36 subscales for RHD cases, Alexandria, Egypt, 2012

QOL Domain	Mean	SD	Lower 95% CL for Mean	Upper 95% CL for Mean
General Health	62.962	18.702	60.354	65.570
Physical functioning	61.433	21.275	85.466	64.399
Role limitations due to physical health problems	66.125	22.750	62.952	69.297
Role limitations due to emotional problems	81.416	23.757	87.103	84.729
Energy/fatigue	61.958	16.762	59.621	64.295
Emotional well-being	72.833	14.973	70.745	74.921
Social functioning	81.083	27.942	77.187	84.979

It is apparent from table 6a that RHD cases of 30 years and above were found to be statistically associated with poor HRQOL in all domains except the role limitations due to emotional problems in comparison with other age groups as revealed by the Post hoc test results. RHD with valve affection had significant influence on the worst HRQOL in the social functioning only (table 6 b,c). Table 6 d shows that RHD cases taking treatments every one month had a significant poor HRQOL in all domains in comparison with other periods between treatments as revealed by the Post hoc test results.

The general perception score was 87.505 ±6.935 and 76.477 ±11.575 before and after the intervention with a highly significant difference.

Figure 1 illustrates the difference in the general perception score among RHD patients before and after the intervention. Distribution of RHD cases according to their level of perception before and after the intervention program is shown in table 7. After the intervention, RHD patients were about seven and half times more likely to have good level of perception compared to RHD cases before the intervention [COR= 0.134, 95% (CI= 0.04 - 0.43)]. There was a highly significant difference in perception before and after the intervention program (X^2MH=13.788, *p*<0.0002). Applying logistic regression analysis, no significant predictors were found to account for difference in perception other than the intervention program.

Table 4: MANOVA general F-test, factors affecting HRQL

Effect	Wilks' Lambda	F	Sig.	Partial Eta Squared	Observed Power
Age	0.726	8.510	0.000	0.274	1.000
Duration	0.937	1.512	0.167	0.063	0.621
Cost	0.939	1.467	0.183	0.061	0.605
Gender	0.941	1.409	0.205	0.059	0.584
Mother education	0.793	1.357	0.106	0.056	0.936
Diagnosis	0.424	1.395	0.007	0.115	1.000
Severity	0.872	1.598	0.078	0.066	0.875
Complications	0.895	2.654	0.013	0.105	0.890
Attacks	0.860	1.773	0.042	0.073	0.913
Period of treatment	0.810	3.018	0.000	0.100	0.997
Regularity of treatment	0.851	1.250	0.205	0.052	0.861
Injection	0.881	3.057	0.005	0.119	0.934
Performance	0.863	1.135	0.307	0.048	0.815

Table 5: MANOVA univariate test

Source	Dependent Variable	F	Sig.	Partial Eta Squared	Observed Power	R^2
Age	General health	9.191	0.003	0.053	0.854	0.354
	Physical functioning	21.621	0.000	0.116	0.996	0.443
	Role limitations due to physical health problems	7.399	0.007	0.043	0.772	0.378
	Role limitations due to emotional problems	2.652	0.105	0.016	0.367	0.252
	Energy/fatigue	32.236	0.000	0.164	1.000	0.513
	Emotional well-being	6.795	0.010	0.040	0.736	0.395
	Social functioning	36.231	0.000	0.181	1.000	0.589
Diagnosis	General health	0.765	0.714	0.065	0.491	0.354
	Physical functioning	0.804	0.672	0.069	0.516	0.443
	Role limitations due to physical health problems	1.800	0.038	0.141	0.921	0.378
	Role limitations due to emotional problems	1.416	0.145	0.115	0.823	0.252
	Energy/fatigue	1.069	0.389	0.089	0.673	0.513
	Emotional well-being	1.179	0.293	0.097	0.728	0.395
	Social functioning	2.533	0.002	0.188	0.987	0.589
Complications	General health	1.215	0.272	0.007	0.195	0.354
	Physical functioning	0.673	0.413	0.004	0.129	0.443
	Role limitations due to physical health problems	1.224	0.270	0.007	0.196	0.378
	Role limitations due to emotional problems	0.710	0.401	0.004	0.133	0.252
	Energy/fatigue	0.911	0.341	0.006	0.158	0.513
	Emotional well-being	0.365	0.546	0.002	0.092	0.395
	Social functioning	10.000	0.001	0.057	0.882	0.589
Attacks	General health	4.998	0.008	0.057	0.808	0.354
	Physical functioning	1.385	0.253	0.017	0.295	0.443
	Role limitations due to physical health problems	1.136	0.324	0.014	0.248	0.378
	Role limitations due to emotional problems	0.835	0.436	0.010	0.192	0.252
	Energy/fatigue	4.509	0.012	0.052	0.763	0.513
	Emotional well-being	5.588	0.004	0.064	0.852	0.395
	Social functioning	7.087	0.001	0.080	0.927	0.589

Injection	General health	10.511	0.001	0.060	0.897	0.354
	Physical functioning	11.420	0.001	0.065	0.919	0.443
	Role limitations due to physical health problems	12.347	0.001	0.070	0.937	0.378
	Role limitations due to emotional problems	6.148	0.014	0.036	0.693	0.252
	Energy/fatigue	7.713	0.006	0.045	0.788	0.513
	Emotional well-being	2.420	0.122	0.015	0.340	0.395
	Social functioning	11.937	0.001	0.068	0.930	0.589
Period between treatments	General health	4.363	014	0.042	0.750	0.42
	Physical functioning	10.554	0.000	0.097	0.988	0.97
	Role limitations due to physical health problems	6.049	0.003	0.058	0.881	0.58
	Role limitations due to emotional problems	5.411	0.005	0.052	0.841	0.52
	Energy/fatigue	9.187	0.000	0.085	0.975	0.85
	Emotional well-being	5.940	0.003	0.057	0.875	0.57
	Social functioning	16.893	0.000	0.146	1.000	0.146

Table 6: Post hoc test using Tukey HSD for multiple comparisons a- Age of patient

Variable	Age	Mean	SD	*p*- value
General health	<15	70.74	16.80	
	15-	65.55	17.41	
	30+	59.46	17.83	0.001
Physical functioning	<15	72.77	19.89	
	15-	64.94	20.09	
	30+	51.86	18.70	0.000
Role limitations due to physical health problems	<15	77.55	23.715	
	15-	66.88	.23.450	
	30+	58.43	18.335	0.000
Energy/fatigue	<15	70.21	15.93	
	15-	65.55	15.46	
	30+	54.26	15.16	0.000
Role limitations due to emotional problems	<15	80.61	14.55	
	15-	74.44	14.63	
	30+	66.82	12.93	0.004
Social functioning	<15	92.28	19.34	
	15-	90.72	19.71	
	30+	67.63	31.65	0.000

Table 6: Post hoc test using Tukey HSD for multiple comparisons (cont.)b- Complication

	Complication	Mean	SD	*p*- value
Social functioning	Regurgitation of valves	68.14	31.70	
	Stenosis of valves	59.77	31.34	
	No complication	90.61	20.27	0.000

Table 6: Post hoc test using Tukey HSD for multiple comparisons (cont.)c- Diagnosis

	Complication	Mean	SD	*p*- value
Social functioning	RHD	85.83	24.31	0.000
	RHD &Valve regurgitation	83.62	26.02	
	RHD &Valve replacement	82.40	29.26	
	RHD &Multiple valves	58.74	31.76	

Table 6: Post hoc test using Tukey HSD for multiple comparisons (cont.)d- Period of treatment

Variable	Period	Mean	SD	*p*- value
General health	2 weeks	66.34	17.95	
	3 weeks	67.61	21.91	
	One month	57.77	16.11	0.011
Physical functioning	2 weeks	65.62	20.98	
	3 weeks	62.38	24.84	
	One month	49.72	17.40	0.000
Role limitations due to physical health problems	2 weeks	68.97	23.80	
	3 weeks	73.21	25.44	
	One month	56.51	15.68	0.003
Role limitations due to emotional health problems	2 weeks	84.25	22.71	
	3 weeks	88.10	20.89	
	One month	71.88	25.06	0.005
Energy/fatigue	2 weeks	64.94	15.67	
	3 weeks	57.14	18.89	
	One month	53.64	17.00	0.000
Emotional well-being	2 weeks	74.98	14.09	
	3 weeks	70.74	18.40	
	One month	66.66	15.61	0.002
Social functioning	2 weeks	87.86	23.38	
	3 weeks	71.42	35.36	
	One month	62.84	31.36	0.000

Table 7: Distribution of RHD patients regarding perception before and after the intervention, Alexandria, Egypt, 2012

Ser.	General score	Pre (53)	Post (53)	COR	*p*-value
1	Good	33	49	0.134 (0.04, 0.43)	X^{2MH}=13.788 P=0.0002*
2	Fair/Poor	20	4		

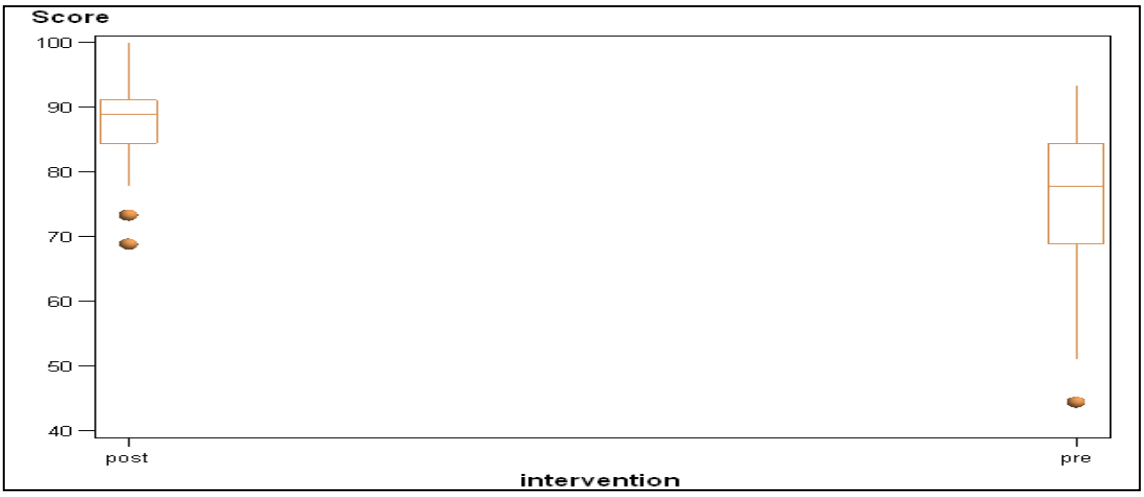

Figure 1: Distribution of RHD patients regarding perception before and after the intervention, Alexandria, Egypt, 2012

DISCUSSION

The present study showed that RHD cases of 30 years and above were found to be statistically associated with poorer HRQOL in all domains except the role limitations due to emotional problems in comparison with other age groups as revealed by the Post hoc test results. RHD with valve affection had significant influence on the worst HRQOL in the social functioning only. RHD cases treated every month had a significant poorer HRQOL in all domains in comparison to other periods of treatment as revealed by the Post hoc test results.

Regarding HRQOL, a study carried out in Brazil among RHD children, showed that the average and total scores for the physical domain including cardiac symptoms and treatment exhibited significant correlation with moderate and severe heart disease in both the patients self-assessment and the parents' proxy assessment.[6] Another study done by Uzark et al., showed that physical functioning of children with mild heart disease does not significantly differ from scores of healthy children.[7]

Although heart disease exerts direct influence on physical health from the medical point of view, most studies concerning HRQOL also reported low scores in the psychological dimensions.[8-11] As regards the emotional dimension, a Brazilian study showed that children with chronic conditions had low scores regarding this issue.[6]

Results of the Brazilian study also strengthen the hypothesis that children with more severe heart disease exhibit lower HRQOL as compared with children with mild disease. Therefore, greater severity of disease was associated with poorer HRQOL.[6] In contrast, another study concluded that the HRQOL of patients with RHD was similar to that found in patients with other chronic diseases, both in terms of physical and psychosocial domains, and that socioeconomic factors were associated with differences in the HRQOL.[2]

Another study carried out in Alexandria showed that school age children with RF had high HRQOL and this could be related to certain factors, such as children's ability to cope with their disease and their responses to the chronic illness stress.[12] Additionally, Petty et al., (2004) cited that RHD in childhood could persist over many years and children may experience disability and dysfunction in adult life which in turn affect their HRQOL.[13]

Moreover, Genevieve et al., cited that the children's commitment with their medications and instruction of health team improved their health status faster and enhanced their HRQOL. Also, Essawy et al., concluded that children with RHD had intellectual decline which affected their own HRQOL.[12]

A study conducted among 71 RHD patients from 5 different hospitals in India showed that 14.1% of the cases underwent surgical correction of valve lesions. Sadly, three cases died due to congestive heart failure and another three due to infective endocarditis. Also, history of recurrent attacks was reported in 67.7% of the cases.[13] A study concerning HRQOL of children after mitral valve replacement using the SF-36 indicated a moderate impairment in general health status for school age children and near normal QOL for the majority of adolescents and young adults.[14] Furthermore, a follow up study of 25 children who underwent surgical valvular repair before the age of 16 years in Brazil demonstrated that the surgical procedure during acute phase of the disease improved the HRQOL of the young RHD patients.[15]

Although all the patients in the Brazilian study attended school, the school functioning dimension was the most affected by disease and it should be noted that the low scores in the school functioning dimension might also be the result of the educational conditions of the Brazilian population.[16]

CONCLUSION AND RECOMMENDATIONS

RHD cases of 30 years and above were found to be statistically associated with poorer HRQOL in all domains except the role limitations due to emotional problems. RHD cases receiving treatments every month had a significant poorer HRQOL in all domains in comparison with other periods of treatment as revealed by the Post hoc test results. After the intervention, RHD patients were about seven and half times more likely to have good level of perception compared to RHD cases before the intervention

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