RESEARCH ARTICLE

Quality of life in patients with rheumatic heart disease

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Abstract

Objective: To assess the quality of life in patients with rheumatic heart disease.

Methods: This case-control study was conducted at the Gulab Devi Chest Hospital, Lahore, Pakistan, from October 2016 to March 2017, and comprised patients with rheumatic heart disease. Convenient sampling technique was used. The 36-item short form health survey was used to collect data. The scores of several dimensions of the questionnaire were calculated and compared using appropriate statistical tests. SPSS 16 was used for data analysis.

Results: Of the 300 subjects, 150(50%) each were cases and controls. There were 45(30%) males and 105(70%) females among the cases and 63(42%) males and 87(58%) females among the controls. The affected individuals reported significant impairment not only in total score ($p<0.001$) but also in all its domains ($p<0.05$ each).

Conclusion: Rheumatic heart disease imposed a considerable burden on the quality of life.

Keywords: Rheumatic fever, Rheumatic heart disease, SF36 questionnaire, Quality of life. (JPMA 68: 370; 2018)

Introduction

Acute rheumatic fever, an inflammatory disease of the heart, joints, central nervous system and subcutaneous tissue, develops after a throat infection by one of the group A β haemolytic streptococci. Rheumatic heart disease (RHD) is usually turned into a chronic state causing congestive heart failure, stroke, endocarditis and death.[1] While the incidence of rheumatic fever and RHD has been decreased in developed countries since the early 20th century, they are still major causes of morbidity and mortality in young age in the developing countries, including Pakistan.[2,3] It is approximated that there are around 15 million cases of RHD worldwide, with 470,000 newly diagnosed cases and 233,000 deaths each year.[4] The prevalence of RHD is more in females compared to the males, because women are house bound and therefore are more likely to be affected by overcrowding.[2] RHD is one of the major causes of early death and disability in Pakistan. The prognosis of patients with RHD is very poor. The beginning of this chronic state usually results in devastating symptoms and physical presentations, all taking part in poor quality of life in these patients.[5]

Quality of life (QoL) is an approximation of remaining life free of deformity, disability or handicap. Although it has widely been explained that all chronic diseases have poor impact on quality of life of patients, each disease has its own characteristics.[6] For example, cancer patients have high levels of anxiety and depression, especially in the months immediately after the diagnosis. QoL consists of two parts. The first part is a physical facet which consists of such things as general health, diet, mental health as well as pain and disease. The second part is psychological in nature and consists of such things as stress, worry, pleasure and other positive or negative emotional states.[6] Chronic rheumatic disease causes stress and anxiety in patients, with increased risks of evolving physical and psychosocial impairments.[7] These include not only pain and fatigue but also difficulties with activities of daily living, ranging from basic household chores to more complex tasks such as paid employment and social roles, e.g. childbearing. Significant progresses in the medical and surgical care have been shown to have good impacts on quality of life in RHD patients, as well as to significantly prolong survival and reduce hospitalisation rates.[8]

The number of studies conducted on quality of life in RHD is scarce and data in a developing country like Pakistan is not available. The current study was undertaken to describe QoL in RHD and to highlight the need to address physical and psychological functioning to ultimately improve QoL of individuals.

Subjects and Methods

This case-control study was conducted at the cardiology department of Gulab Devi Chest Hospital, Lahore, Pakistan, from October 1, 2016, to March 31, 2017, and comprised consecutive patients of either gender admitted with RHD. Controls were the healthy attendants

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ANNEXURE

Standard Form – 36 (SF-36)

Patient Name:		Date:
Age:	Gender:	

Standard Form 36 Survey: The SF-36 Form is one of many outcomes assessments designed by the Medical Outcomes Trust in Boston, MA. It is designed to approximate the improvement in health status from a medical intervention.
INSTRUCTIONS: This survey asks for views about your health. This information will help keep track of how you feel and how well you are able to do your usual daily activities. Answer every question marking the answer as indicated. If you are unsure about how to answer a question, please give the best answer you can.

1. In general, would you say your health is: (Circle One)	1. Excellent 2. Very Good 3. Good 4. Fair 5. Poor
2. Compared to one year ago, how would you rate your health in general at this time? (Circle One)	1. Much better now than one year ago 2. Somewhat better now than one year ago 3. About the same as one year ago 4. Somewhat worse that one year ago 5. Much worse now than one year ago

3. The following items are about activities you might do during a typical day. Does your health now limit you in these activities? If so, how much? (Circle the appropriate number for each question)

Activities	Yes, limited a lot	Yes, limited a little	No, not limited
a. Vigorous activities, such as running, lifting heavy Objects, or participation in strenuous sports	1	2	3
b. Moderate activities, such as moving a table, Vacuuming, bowling or golfing	1	2	3
c. Lifting or carrying groceries	1	2	3
d. Climbing several flights of stairs	1	2	3
e. Climbing one flight of stairs	1	2	3
f. Bending, kneeling, or stooping	1	2	3
g. Walking more than a mile	1	2	3
h. Walking several blocks	1	2	3
i. Walking one block	1	2	3
j. Bathing or dressing yourself	1	2	3

4. During the past 4 weeks, have you had any of the following problems with your work or other regular activities as a result of your physical health? (Circle the appropriate number for each question)

a. Cut down on the amount of time you spent on work or other activities	Yes = 1	No = 2
b. Accomplished less than you would like	Yes = 1	No = 2
c. Were limited in the kind of work or other activities	Yes = 1	No = 2
d. Had difficulty performing the work or other activities (For example – requiring an extra effort)	Yes = 1	No = 2

5. During the past four weeks, have you had any of the following problems with your work or other regular daily activities as result of any emotional problems (such as feeling depressed or anxious)? (Circle the appropriate number for each question)

a. Cut down on the amount of time you spent on work or other activities	Yes = 1	No = 2
b. Accomplished less than you would like	Yes = 1	No = 2
c. Didn't do work or other activities as carefully as usual	Yes = 1	No = 2
6. During the past 4 weeks, to what extent has your physical health or emotional problems interfered with your normal social activities with family, friends, neighbors or groups? (Circle one)	1. Not at all 2. Slightly 3. Moderately 4. Quite a bit 5. Extremely	
7. How much bodily pain have you had during the past 4 weeks? (Circle one)	1. None 2. Very mild 3. Mild 4. Moderate 5. Severe 6. Very severe	
8. During the past 4 weeks, how much did pain interfere with your normal work (including both work outside the home and housework)? (Circle one)	1. Not at all 2. Slightly 3. Moderately 4. Quite a bit 5. Extremely	

9. These questions are about how you feel and how things have been with you during the past 4 weeks. For each question, please give the one answer that comes closest to the way you have been feeling. How much of the time during the past 4 weeks: (Circle one number on each line)

	All of the time	Most of the time	A good bit of the time	Some of the time	A little of the time	None of the time
a. Did you feel full of pep?	1	2	3	4	5	6
b. Have you been a very nervous person?	1	2	3	4	5	6
c. Have you felt so down in the dumps that nothing could cheer you up?	1	2	3	4	5	6
d. Have you felt calm and peaceful?	1	2	3	4	5	6
e. Did you have a lot of energy?	1	2	3	4	5	6
f. Have you felt downhearted and blue?	1	2	3	4	5	6
g. Did you feel worn out?	1	2	3	4	5	6
h. Have you been a happy person?	1	2	3	4	5	6
i. Did you feel tired?	1	2	3	4	5	6

10. During the past 4 weeks, how much of the time has your physical health or emotional problems interfered with your social activities (like visiting friends, relatives etc.)?(Circle one)	1. All of the time 2. Most of the time 3. Some of the time 4. A little of the time 5. None of the time

11. How TRUE or FALSE is each of the following statements to you? (Circle one for each line).

	Definitely True	Mostly True	Don't Know	Mostly False	Definitely False
a. I seem to get sick easier than other people	1	2	3	4	5
b. I am as healthy as anybody I know	1	2	3	4	5
c. I expect my health to get worse	1	2	3	4	5
d. My health is excellent	1	2	3	4	5

of the patients, had no history of rheumatic fever or RHD, and were matched cases for age. Patients with a history of ischaemic, congenital or non-RHDs were excluded. Convenient sampling technique was used to collect data and the 36-item Short Form Health Survey (SF36) questionnaire was used for the purpose (Annexure). After obtaining approval from the institutional ethics committee and informed verbal consent from the patients, the subjects were asked about their socio-demographic profile. Initially, there was an attempt at using a self-administration method, but this strategy resulted in a high rate of unanswered questions because of the language problem; thus it was decided to conduct direct interviews which lasted 15-20 minutes. The interviewees did not have difficulties in understanding the questions.

Both descriptive and inferential statistical analyses were done using SPSS 16. Qualitative data was presented in the form of frequencies along with percentages. Quantitative data was presented in the form of mean, standard deviation, median and interquartile range (IQR) by simple descriptive analysis. We calculated the total score and also the score of each domain as per the scoring system used in literature.[9] The normality of each domain was checked using one sample Kolmogorov-Smirnov test. All data was non-normally distributed, and as parametric tests could not be applied on non-normal data, so it was analysed using Mann-Whitney U test. Qualitative data like gender was analysed using chi-square test.

Results

Of the 300 subjects, 150(50%) each were cases and controls. There were 45(30%) males and 105(70%) females in the experimental group and 63(42%) males and 87(58%) females in the control group (p=0.030). The mean age of cases was 33.77±12.19 years and that of the controls was 34.66±12.38 years (p=0.689) (Table-1).

When the data was checked for assumptions using

Table-1: Patients' sociodemographic characteristics.

		Cases (n=150)	Controls (n=150)	p-value*
Gender no(%)				
Males		45(30)	63(42)	0.030
Females		105(70)	87(58)	
Age (years)	Mean±S.D.	33.77±12.19	34.66±12.38	0.689
	Median ± IQR	32.00 ± 18.00	33.00 ± 17.25	

*Mann Whitney U test was applied to calculate the p value for age and Chi square test for gender
IQR:Interquartile range
SD: Standard deviation.

Table-2: Distribution behaviour of the data.

SF 36 scales	Kolmogorov-Smirnov Z Value	p-value*	Distribution
General health	1.404	0.039	Non-normal
Physical functioning	1.876	0.002	Non-normal
Role functioning/Physical	5.074	<0.001	Non-normal
Role functioning/emotional	4.791	<0.001	Non-normal
Emotional well-being	1.282	0.075	Non-normal
Bodily pain	1.845	0.002	Non-normal
Vitality	1.488	0.024	Non-normal
Social functioning	2.254	<0.001	Non-normal
Health change	3.849	<0.001	Non-normal
Total score	2.739	<0.001	Non-normal

*Kolmogorov Smirnov Z test was used to check the assumptions
SF-36:36-item Short Form Health Survey.

Table-3: Comparison of SF 36 scales between rheumatic heart disease patients and the general population.

Parameters	Study Groups	Mean ± S.D.	Median ± IQR	p-Value*
General Health	Case	209.60 ± 83.87	200.00 ± 125.00	<0.001
	Control	303.33 ± 88.40	300.00 ± 131.25	
	Total	256.47± 98.00	250.00 ± 150.00	
Physical Functioning	Case	364.00 ± 218.14	350.00 ± 350.00	<0.001
	Control	734.67 ± 275.99	800.00 ± 412.50	
	Total	549.33± 310.05	550.00 ± 538.00	
Role functioning/ Physical	Case	52.66 ± 105.35	0.00 ± 100.00	<0.001
	Control	234.00 ± 161.29	300.00 ± 300.00	
	Total	143.33 ± 163.53	100.00 ± 300.00	
Role functioning/ Emotional	Case	70.00 ± 96.06	0.00 ± 100.00	<0.001
	Control	135.33 ± 123.77	100.00 ± 300.00	
	Total	102.67 ± 115.34	100.00 ± 200.00	
Emotional well being	Case	240.93 ± 100.77	230.00 ± 160.00	0.001
	Control	282.00 ± 97.72	280.00 ± 125.00	
	Total	261.47 ± 101.20	260.00 ± 155.00	
Bodily Pain	Case	73.90 ± 62.06	85.00 ± 90.00	<0.001
	Control	132.20 ± 54.60	135.00 ± 90.00	
	Total	103.05± 65.25	110.00 ± 110.00	
Vitality	Case	132.13 ± 68.85	120.00 ± 100.00	<0.001
	Control	220.93 ± 85.83	210.00 ± 125.00	
	Total	177.00 ± 75.37	180.00 ± 100.00	
Social Functioning	Case	101.33 ± 63.31	100.00 ± 100.00	0.004
	Control	122.00 ± 55.40	125.00 ± 100.00	
	Total	111.67 ± 60.28	100.00 ± 125.00	
Health Change	Case	63.33 ± 30.33	75.00 ± 50.00	<0.001
	Control	46.50 ± 26.07	50.00 ± 50.00	
	Total	54.92± 29.46	50.00 ± 50.00	
Total Score	Case	1307.90 ± 509.21	1260.00 ± 762.50	<0.001
	Control	2210.96 ± 684.35	2330.00 ± 1063.75	
	Total	1008.33± 576.59	805.00 ± 760.00	

*Mann Whitney U test was applied to calculate the p-Values.
SF-36:36-item Short Form Health Survey.
IQR: Interquartile range
SD: Standard deviation.

Kolmogorov-Smirnov Z-test, it showed that the data was non-normally distributed and non-parametric test was applied (Table-2).

The patients had significantly reduced scores in all QoL aspects compared with the controls, indicating that there was a relationship between the two. The affected individuals reported significant impairment not only in total score (p<0.001) but also in all domains, including general health (p<0.001), physical functioning (p<0.001), role functioning/physical (p<0.001), role functioning/ emotional (p<0.001), emotional well-being (p=0.001), vitality (p<0.001), bodily pain (p<0.001), social functioning (p=0.004) and health change (p<0.001). The most significant differences were observed in total score (1307.90 vs. 2210.96), general health subscale (209.60 vs. 303.33), physical functioning (364.00 vs. 734.67), role functioning/physical (52.66 vs. 234.00), role functioning/ emotional (70.00 vs. 135.33), vitality (132.13 vs. 220.93) and bodily pain (73.90 vs. 132.20). The lowest differences although significant were seen for emotional well-being (240.93 vs. 282.00), social functioning (101.33 vs. 122.00) and health change (63.33 vs. 46.50) (Table-3).

Discussion

Literature on QoL assessment in patients with RHD is rare despite the availability of questionnaires developed and validated to assess individuals with chronic diseases. The current study is the first to the authors' knowledge that has objectively examined QoL among patients with RHD in Pakistan. RHD, mostly neglected by media and government, is a major burden in developing countries like Pakistan[2,10-12] where it is one of the most common causes of the cardiovascular morbidity and mortality in young people.[13] Patients diagnosed with the disease experience severe difficulties due to complications caused by this disease such as atrial fibrillation,[14] stroke,[15] and consequently often have problems in maintaining normal daily activities.

The present data demonstrated a significant relationship between RHD and poor QoL in mostly young people. Our study showed that the likelihood of an RHD patient having poor QoL was greater than a healthy individual (p<0.001). Comparison of the present study sample with a sample of patients with rheumatic fever showed a correlative pattern of deterioration.[7] Although heart disease employs a significant impact on physical health from the medical point of view,[16] most studies on quality of life also reported low scores in the psychosocial aspects,[17,18] as were found in the present study. Low scores in the emotional dimension show the suffering of patients from their chronic illness.[18,19] Stress and anxiety symptoms can have a negative effect on treatment outcomes in chronic disease and lead to reduced QoL and increased disability and deterioration.[20] Adolescents with severe heart disease reported higher level of anxiety and depression as compared to the age-matched healthy controls.[19] Study on QoL in adults with congenital heart diseases showed that inoperable conditions had a trend towards a poorer quality of life.[21] Some studies have used other questionnaires such as the Paediatric Quality of Life Inventory (PedsQL), which was executed to children with cardiac diseases and their guardians, and these studies have found conflicting results regarding QoL of the children investigated.[22] Lane et al.[23] showed that arthritis and RHD negatively affected several sides in QoL, such as the work, and home activities compared to individuals without chronic disease; these findings are also confirmed by our study. Regarding cognitive problems, it is stated that individuals with rheumatic fever may exhibit profound reversible cognitive problems, such as poor attention and concentration.[24] Khalil et al.[25] explained that patients with chronic RHD had intellectual decline. Bodily pain is one of the major manifestations of rheumatic fever that lead to sleeping difficulties in patients,[12] as were found in the present study.

QoL was assessed using a well-validated tool, the SF36 health questionnaire.[26,27] SF36 has been used many times among different patients and in many countries; however, this was the first time that this tool was used in Pakistan for examining the QoL in RHD patients, which is not a feature of comparable studies and so is a novel work, which could augment and intensify the outcomes of this study.

The current study had a few limitations as well. The sample size was small compared to the disease burden in Pakistan. Moreover, we used the English version of SF36 questionnaire and more than 90percent of our patients could not understand it and were unable to answer, so we had to take direct interviews afterwards. A better option would be to administer the Urdu version of the questionnaire. It would be easier for the respondents to understand and answer the questions without any difficulty.

Conclusion

Subjective health-related QoL in RHD patients was significantly impaired and was much worse than the controls. Rheumatic heart disease imposes a substantial burden on QoL. The burden can be reduced through prevention, rehabilitation and other disease management strategies. By using the SF36 questionnaire in the beginning of the follow-up, physicians can define their

QoL profile better. Psychotherapy sessions can also help in improving QoL.

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