

Quality of Life of Patients with Haemophilia

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ABSTRACT

Objectives: The aim of this study was to assess the quality of life of patients with haemophilia attending Government Medical College Hospital, Kottayam and to find out the association between quality of life of patients with haemophilia and selected variables.

Materials and Method: A quantitative research approach was used for the study. The research design selected for the study was non experimental descriptive design. A total of 80 patients, attending haemophilia clinic in Medical College Hospital, Kottayam were selected for the study by using non probability purposive sampling technique. The data collection instruments for the study included socio personal and clinical data sheet for collecting basic information and Hemofilia QOL questionnaire for assessing quality of life. The data was analyzed by using descriptive and inferential statistics.

Results: Majority of patients (68.8%) had moderately good quality of life. There was no association between quality of life of patients with selected variables like age, education, occupation, marital status, monthly family income, type and severity of haemophilia and comorbidities.

Keywords: *Haemophilia; Quality of life.*

BACKGROUND

Haemophilia is a hereditary bleeding disorder caused by deficiency of either coagulation factor VIII, haemophilia A or coagulation factor IX, haemophilia B and classified as severe, moderate or mild depending upon the plasma level of the coagulation factor. Due to the sex linkage of the disorder, there is a greater prominence in males than in females. It appears worldwide and occurs in all racial groups. The number of affected persons worldwide is estimated to be about 400,000. Haemophilia A is more common than haemophilia B, representing 80-85% of the total.¹

An observational cross sectional study carried out at the Regional Blood Center of Juiz de Fora , Minas Gerais , aimed to measure health related quality of life in adults with haemophilia and also aimed to describe

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socioeconomic aspects and health conditions of these individuals in the context of health related quality of life. The study evaluated 39 patients, ages ranged from 18 to 79 years, in which 33 had haemophilia A and six had haemophilia B. In eight cases haemophilia was classified as mild, in 16 as moderate haemophilia and in 15 cases as severe haemophilia. Comorbidities reported by the patients were asthma, arthritis, cancer, heart disease, depression, hypertension, chronic low back pain and smoking, 66.7% considered themselves sedentary and 15.4% had a body mass index greater than 25 kg/m². Records of four patients showed sero positivity for anti HIV and 2 for anti HCV. The average Haem A QOL total score was 35.33, ranging from 0 to 79.54. The dimensions 'Sports and Leisure' and 'Physical Health' had the highest averages (49.89 and 43.30, respectively) indicating poorer quality of life and the dimension 'Relationships and Partners' was the least impaired dimension among the participants (mean 17.52). The result highlights the impact of haemophilia on quality of life of patients.²

Complications such as recurrent bleeding, affect the productivity of people with haemophilia and their caregivers in terms of absenteeism from work and / or

school. Those patients with inhibitors are at increased risk for bleeding and associated complications. These bleeding episodes also affect the quality of patients with haemophilia. So the investigator identified a felt need to conduct a study regarding the quality of life of patients with haemophilia.

MATERIAL AND METHOD

A quantitative research approach was used for the study. The research design selected for the study was non experimental descriptive design. A total of 80 patients, attending haemophilia clinic in Medical College Hospital, Kottayam were selected for the study by using non probability purposive sampling technique. The data collection instruments for the study included socio personal and clinical data sheet for collecting basic information and A36 Hemofilia QOL Quality of life questionnaire.

Socio personal data sheet consisted of 7 items which include age, education, occupation, marital status, religion and native district of patients with haemophilia. It was filled by the investigator. Clinical data sheet consisted of 8 items which includes type of haemophilia, severity, comorbidities, frequency of hospitalization, family history, presence of siblings affected with haemophilia, history of death of relatives due to haemophilia and parental consanguinity. It was filled by the investigator. . A36 Hemofilia QOL Quality of life questionnaire is a standardized disease specific questionnaire for the assessment of the health related quality of life of people living with haemophilia. The domains are physical health, daily activities, treatment satisfaction, mental aspects, relationships and social activities. There are 36 items, each question has five options. There are four reversely scored questions. Subscales (domains) items in the questionnaire include

Physical health : 1, 2, 3, 4, 5, 6, 7, 8, 13, 14, 15, 16, 17

Daily activities : 9, 10, 11, 12

Treatment satisfaction : 18*, 19*, 20, 21, 22*, 23

Mental health : 24, 25, 26, 27, 28*, 29, 30, 31

Relationships and social activities : 32, 33, 34, 35, 36

* Score should be reversed for the items 0=4, 1=3, 2=2, 3=1 and 4=0.

Maximum score of each question is 4 and minimum score is 0. Total score of questionnaire is 144. Tools were given along with the evaluation criteria to 9 nursing experts in nursing, haematology and medicine for ensuring content validity. The reliability of A36 Hemofilia QOL - Quality of life questionnaire was done by test retest method using Karl Pearson correlation coefficient and it was 0.92, thus the tool was found to be reliable.

FINDINGS

- Results of the study were discussed under the following headings:
- Socio personal data of patients with haemophilia
- Clinical data of patients with haemophilia
- Quality of life of patients with haemophilia
- Association between quality of life of patients with haemophilia and selected variables
- Socio personal data of patients with haemophilia
- Majority of the patients (43.75%) belonged to the age group of 13-22 years and majority of patients (58.80%) were studied up to high school. Most of the patients (38.75%) were students, 12.50% were government employee, 30% were private employee or self employed and 18.75% of patients were unemployed. Most of them (67.50%) were single and belonged to Hindu religion (58.75%). Majority of patients (47.50%) were from Kottayam district.
- Clinical data of patients with haemophilia
- Majority of patients (71.20%) had haemophilia A and had severe haemophilia (65%). Most of the patients (78.75%) were free from Comorbidities. Majority of patients (46.25%) were not hospitalized, 20% admitted once, 15% twice and 18.75% were more than three times admitted during the previous year. More than half of the patients (52.50%) had family history of haemophilia. Majority (68.80%) had no haemophilia affected siblings and 31.20% had siblings with haemophilia. Most of the patients (72.50%) had no relatives who died due to haemophilia. Majority of patients (95%) had no parental consanguinity.

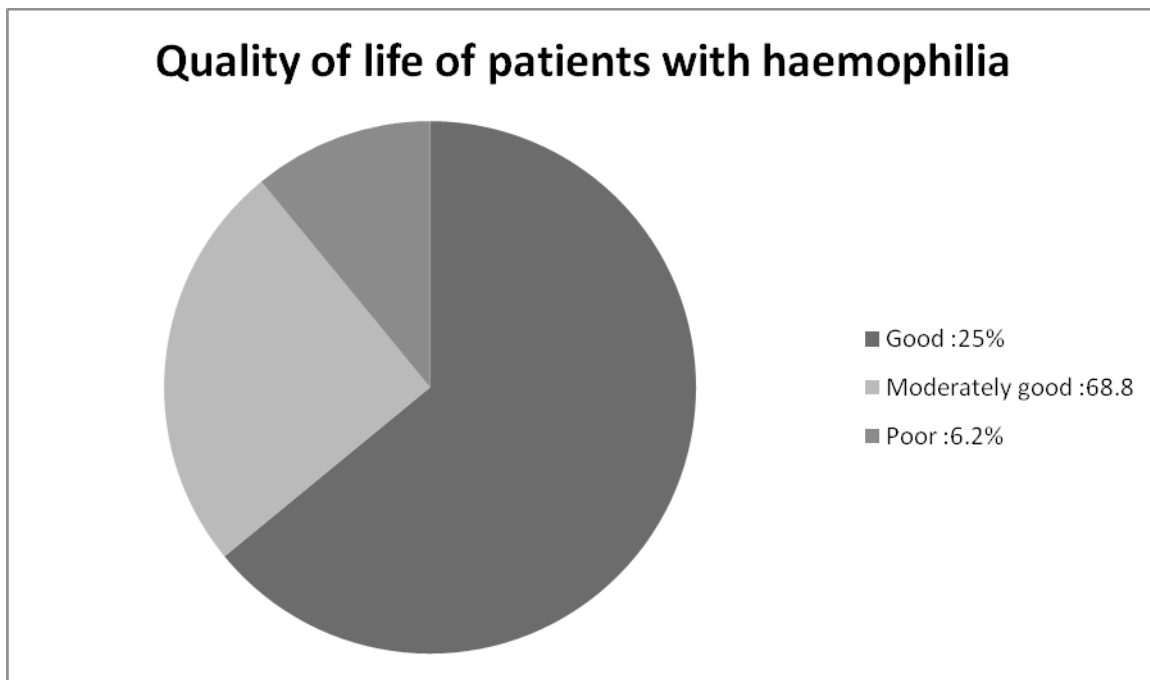


Figure 1 : Pie diagram showing the quality of life of patients with haemophilia

Pie diagram depicts the quality of life of patients with haemophilia. Majority of patients (68.8%) had moderately good quality of life, 25% had good quality of life and only 6.2% had poor quality of life.

Table 1: Frequency distribution and percentage of patients with haemophilia based on domains of quality of life (n=80)

Domains of quality of life	Good		Moderately good		Poor	
	f	%	f	%	f	%
Physical health	17	21.25	53	66.25	10	12.50
Daily activities	11	13.75	42	52.50	27	33.75
Treatment satisfaction	40	50.00	39	48.80	1	1.20
Mental health	19	23.80	40	50.00	21	26.20
Relationship and social activities	28	35.00	34	42.50	18	22.50

Table 1 reveals that majority of patients (66.25%) had moderately good physical health and 33.75% were poor. More than half of the patients (52.50%) were moderately good in daily activities and half of the patients (50%) had good treatment satisfaction. Half of the patients (50%) had moderately good mental health and 42.50% were moderately good in relationships and social activities.

Association between quality of life of patients with haemophilia and selected variables

The null hypothesis was stated as follows:

H_{01} : There is no significant association between quality of life of patients with haemophilia and selected variables.

Table 2: Frequency distribution and chi square value of quality of life patients with haemophilia and age (n=80)

Age in years	Quality of life			df	χ^2
	Good	Moderate	Poor		
	f	f	f		
13-22	7	25	3		
23-32	8	14	1		
33-42	2	9	0	8	6.37
43-52	2	2	1		
≥53	1	5	0		

Table 3: Frequency distribution and chi square value of quality of life of patients with haemophilia and education (n=80)

Education	Quality of life			df	χ^2
	Good	Moderate	Poor		
	f	f	f		
Primary	1	3	0	6	7.05
High school	9	34	4		
Graduation	7	17	1		
Post graduation or above	3	1	0		

Table 4: Frequency distribution and chi square value of quality of life of patients with haemophilia and marital status (n=80)

Marital status	Quality of life			df	χ^2
	Good	Moderate	Poor		
	f	f	f		
Single	16	34	4	2	2.29
Married	4	21	1		

Table 5: Frequency distribution and chi square value of quality of life of patients with haemophilia and type of haemophilia (n=80)

Type of haemophilia	Quality of life			df	χ^2
	Good	Moderate	Poor		
	f	f	f		
Hemophilia A	13	40	4	2	0.63
Hemophilia B	7	15	1		

Table 6: Frequency distribution and chi square value of quality of life of patients with haemophilia and severity of haemophilia (n=80)

Severity of haemophilia	Quality of life			df	χ^2
	Good	Moderate	Poor		
	f	f	f		
Severe	13	36	3		
Moderate	2	13	0	4	6.12
Mild	5	6	2		

Tables show that the obtained chi-square values are statistically not significant. Hence there is no association between quality of life of patients with haemophilia with selected variables.

DISCUSSION

The present study was aimed to evaluate the quality of life of patients with haemophilia at Government Medical College Hospital, Kottayam. The findings of the study were discussed in terms of its objectives and hypotheses. In the present study data regarding the quality of life were collected from patients with haemophilia. The data were analyzed by descriptive and inferential statistics.

Description of sample characteristics

In the present study the sample characteristics show that majority of patients (43.75%) belonged to the age group of 13-22 years, 28.75% belonged to the age group of 23-32 years. Majority of patients (58.80%) were studied up to high school. While considering occupation, most of the patients (38.75%) were students. The study findings were consistent with the findings of a cross sectional descriptive survey design which was done in Manipal Haemophilia Society, Kasturba Hospital Manipal. The data collected from 49 patients who were attended the haemophilia summer camp in that most of the subjects (45%) were belonged to 20 to 30 years of age group. Most of them were studying in higher secondary.³

The present study identified that majority of patients (71.20%) had haemophilia A and 28.80% had haemophilia B. Majority (65%) had severe haemophilia, 18.75% had moderate and 16.25% had moderate haemophilia. These findings were congruent with the findings reported by Parthiban et al in which both

haemophilia A and B showed 66% of cases with severe factor deficiency, 26% with moderate, and 8% with mild deficiency.⁴ According to the present study most of the patients (78.75%) were free from comorbidities and 10% had hypertension, 3.75% had diabetes mellitus, 1.25% had dyslipidemia and 6.25% had other diseases like renal calculi and HCV. A retrospective observational study identified patients diagnosed with haemophilia A and B using medical and pharmacy electronic medical records and data from Centro Hospitalar Sao Joao is consistent with these findings. A cohort of 103 patients were identified in which a small number of patients (n=8; 7.8 %) were HIV-positive and 22 patients were HCV-positive (21.4%).⁵ The family history was present among more than half of the patients (52.50%) in present study. Similar percentage was reported by Parthiban et al in which 52.2% of the patients had family history of haemophilia.⁴

Quality of life of patients with haemophilia

In the present study majority of patients (68.8%) had moderately good quality of life, 25% had good quality of life and only 6.2% had poor quality of life. These findings were congruent with an observational cross sectional study to describe the clinical profile of haemophiliac patients and their quality of life in Western Uttar Pradesh. The mean total HAEMO QOL scores were 39.6 ± 15.0 for the children and 47.4 ± 14.1 for the adult patients respectively. This implies that the patients of hemophilia had low QOL. In addition, patients with severe haemophilia had lower QOL than mild and moderate patients.⁶ The present study assessed the domains of quality of life. Majority of patients (66.25%) had moderately good physical health, more than half of the patients (52.50%) were moderately good in daily activities and half of the patients (50%) had

good treatment satisfaction. Half of the patients (50%) had moderately good mental health and 42.50% were moderately good in relationships and social activities. Similar findings were reported by a study which assessed the quality of life in patients with haemophilia. The mean score of quality of life in all patients was 71.88 (26.89 SD), which is in the moderate to poor group. According to the results obtained in each subscale associated with defined domains, patients were examined separately and in terms of physical health (51.15%) and treatment satisfaction (67.37%), patients were in moderate to good range and in daily activities (45%), mental health (48.41%) and relationships and social activities (47.9), patients were in moderate to poor range.⁷

CONCLUSION

Haemophilia is a congenital bleeding disorder characterized by spontaneous and potentially life threatening bleeding episodes. Haemophilia incurs tremendous intangible costs including reduced quality of life, pain and suffering and the emotional and physical toll on the patient and caregivers

Conflict of Interest : There is no economical burden to the subjects

Source of Funding: Self

Ethical Clearance: Ethical clearance obtained and informed consent were obtained.

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