A study of the impact of Haemophilia on education, employment and joint health among patients treated at the Yangon General Hospital

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Abstract

A hospital-based cross-sectional analytical study was carried out on 53 patients with haemophilia A at the Department of Clinical Haematology, Yangon General Hospital during the period of October 2014 to September 2016. Haemophilia Joint Health Score (HJHS) and Functional Independence Score in Haemophilia (FISH) were used to assess the patients' physical well-being. All patients were males with a mean age of 23.18 ± 10.2 years (r = 12-55). Twenty-four patients (45.3%) discontinued their education and among them 66.7% discontinued due to pain with recurrent bleeding in the joints and 33.3% discontinued due to other reasons. Seventeen patients (32.08%) in this study were students, while another 17 patients (32.08%) were workers/employed and 19 patients (35.85%) discontinued working. Out of 19 patients who discontinued working, 84.21% discontinued due to severity of the disease and 15.79% discontinued due to personal and religious reasons. Mean HJHS was 41.75 ± 17.85 (range = 10-89) and mean FISH was 23.74 ± 4.07 (range = 13-31) in this study. This study highlighted that haemophilia A had a significant impact on the education, employment and joint health of haemophilia patients in Myanmar but severity of haemophilia was not found to have statistically significant different impact on the education, employment and joint health status of haemophilia A patients.

Keywords: Haemophilia A, HJHS, FISH, Education, Employment

Introduction

Haemophilia A is a rare congenital bleeding disorder linked to X-chromosome and inherited in a recessive manner. Haemophilia A (HA) is more common than haemophilia B (HB), representing 80-85% of the total haemophilia cases in the population.[1]

People suffering from haemophilia battle with problems such as frequent joint and muscle bleedings throughout their lives. Majority of people with haemophilia globally do not have access to appropriate care when such bleeding occurs. Poor joint health like chronic haemarthroses and crippling arthropathy can lead to severe disability as a result of improper joint care. These complications in turn have a significant impact on the day-to-day function of patients with haemophilia.[2] Education and employment

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can also be severely impacted as a result of poor joint health.[2, 3] Collection of outcome data using Haemophilia Joint Health Score (HJHS) and Functional Independence Score in Haemophilia (FISH) can enable clinicians to judge the efficacy of treatment regimens, justify the resources utilized and advocate for the well-being of haemophilia patients.[4, 5]

Objectives

The study was carried out to find out the impact of haemophilia A disease on education, employment and joint health of the patients in Myanmar.

Materials and Methods

The study was a hospital-based cross-sectional analytical study carried out at the Department of Clinical Haematology, Yangon General Hospital (YGH). A total of 53 adult Myanmar patients with haemophilia A treated at the Department of Clinical Haematology, YGH during the period October 2014 to September 2016 were studied. Severity of haemophilia in these patients was classified as mild, moderate and severe by using International Society on Thrombosis and Haemostasis (ISTH) criteria.[6] The data on education status and employment status in each of the patients were also collected and analysed. The health status of the joints was assessed by using Haemophilia Joint Health Score (HJHS) and Functional Independence Score in Haemophilia (FISH).[4, 5]

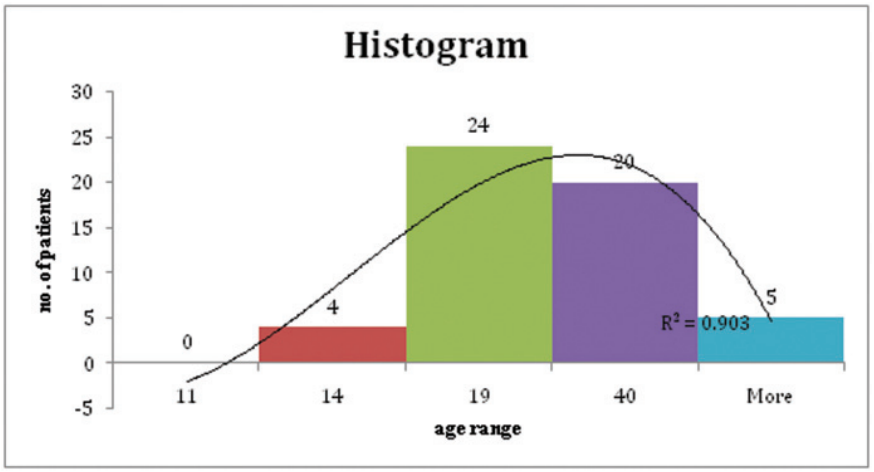
Statistical analysis

Data were checked for completeness, errors and inconsistencies prior to entry on spread sheets and statistical analysis was done using SPSS 16.0 package.

Results

All 53 patients were males. The youngest patient was 12 years-old and the eldest 55 years-old. Mean age of the patients was 23.18 ± 10.2 years (r = 12-55) (Figure 1).

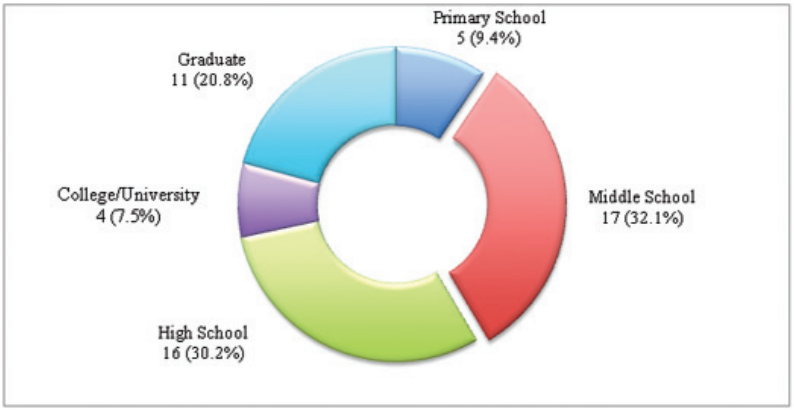
Figure (1). Age distribution of patients with haemophilia A (n = 53)



Thirty-nine patients (73.6%) had severe haemophilia A, while 9 patients (17%) had moderate haemophilia A and 5 patients (9.4%) had mild haemophilia A.

Five patients (9.4%) had primary school level education, while 17 patients (32.1%) had middle school level education, 16 patients (30.2%) had high school level education, 4 patients (7.5%) had college/university level education and 11 patients (20.8%) had graduate level education (Figure 2).

Figure (2). Education status of patients with haemophilia A (n = 53)



Twenty-four patients (45.3%) had discontinued their education and 29 (54.7%) continued their education. Out of 24 patients who discontinued their education, 16 patients (66.7%) discontinued due to recurrent joint bleeding and 8 patients (33.3%) discontinued for reasons not related to the joint problem such as financial, social and personal problems.

The association between severity of haemophilia A and education status was shown in Table (1). The education was not observed to be significantly affected by severity of haemophilia (P value = 0.771).

Table (1). Association between severity of haemophilia A patients and their education status (n = 53)

Severity	Education status					Total
	Primary School	Middle School	High School	College/ University	Graduate	
Mild	1 (20%)	1 (20%)	2 (40%)	0 (0%)	1 (20%)	5 (100%)
Moderate	2 (22.2%)	2 (22.2%)	3 (33.3%)	1 (11.1%)	1 (11.1%)	9 (100%)
Severe	2 (5.1%)	14 (35.9%)	11 (28.2%)	3 (7.7%)	9 (23.1%)	39 (100%)
Total	5 (9.4%)	17 (32.1%)	16 (30.2%)	4 (7.5%)	11 (20.8%)	53 (100%)

Chi-square = 4.871 P value = 0.771

The association between the severity of haemophilia A and discontinuation of education is shown in Table(2). There was no statistically significant association between the severity of haemophilia and discontinuing education (P value = 0.224).

Table (2). Association between severity of haemophilia A and discontinued education (n = 53)

Severity	Discontinued education status		Total
	Discontinued education	Continued education	
Mild	1 (20%)	4 (80%)	5 (100%)
Moderate	6 (66.7%)	3 (33.3%)	9 (100%)
Severe	17 (43.6%)	22 (56.4%)	39 (100%)
Total	24 (45.3%)	29 (54.7%)	53 (100%)

Chi-square = 2.996 P value = 0.224

The association between the severity of haemophilia A and discontinuation of education due to disease is shown in Table (3). There was no statistically significant association between the severity of haemophilia and discontinuing education due to disease (P value = 0.767).

Table (3). Association between severity of haemophilia A and discontinued education due to disease (n = 24)

Severity	Discontinued education		Total
	Due to disease	Not due to disease	
Mild	1 (100%)	0 (0%)	1 (100%)
Moderate	4 (66.7%)	2 (33.3%)	6 (100%)
Severe	11 (64.7%)	6 (35.3%)	17 (100%)
Total	16 (66.7%)	8 (33.3%)	24 (100%)

Chi-square = 0.529 P value = 0.767

Regarding the employment status, 17 patients (32.08%) were students, while another 17 patients (32.08%) were workers/employed and 19 patients (35.85%) have discontinued working. Out of 19 patients who discontinued working, 16 patients (84.21%) discontinued due to recurrent joint bleeding and 3 patients (15.79%) discontinued due to personal and religious reasons that were not related to the joint problem.

Table (4) shows the association between the severity of haemophilia A and employment status. The employment was not observed to be significantly affected by severity of haemophilia (P value = 0.465).

Table (4). Association between the severity of haemophilia A patients and their employment status (n = 53)

Severity	Employment status			Total
	Student	Employed	Dependent	
Mild	3 (60%)	1 (20%)	1 (20%)	5 (100%)
Moderate	2 (22.22%)	2 (22.22%)	5 (55.56%)	9 (100%)
Severe	12 (30.77%)	14 (35.90%)	13 (33.33%)	39 (100%)
Total	17 (32.08%)	17 (32.08%)	19 (35.85%)	53 (100%)

Chi-square = 3.5802 P value = 0.465

The association between the severity of haemophilia A and discontinuation of employment is shown in Table (5). There was no statistically significant association between the severity of haemophilia and discontinuing employment (P value = 0.879).

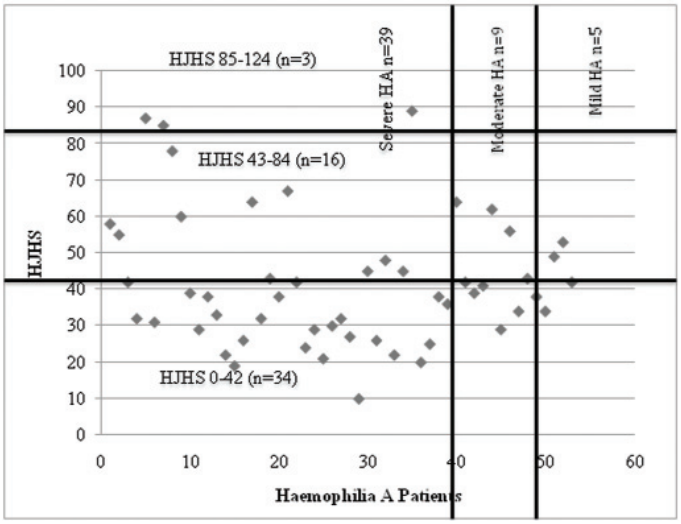
Table (5). Association between the severity of haemophilia A and discontinuation of employment (n = 19)

Severity	Discontinued employment status		Total
	Due to disease	Not due to disease	
Mild	1 (100%)	0 (0%)	1 (100%)
Moderate	4 (80%)	1 (20%)	5 (100%)
Severe	11 (84.62%)	2 (15.38%)	13 (100%)
Total	16 (84.21%)	3 (17.79%)	19 (100%)

Chi-square = 0.256 P value = 0.879

In 53 patients with haemophilia A in the study (Figure 3), the minimum HJHS was 10, maximum was 89 and mean was 41.75 ± 17.85. In patients with mild haemophilia A, minimum HJHS was 34, while maximum was 53 and mean was 43.2 ± 7.7. In patients with moderate haemophilia A, minimum HJHS was 29, maximum was 64 and mean was 45.5 ± 12.3. In patients with severe haemophilia A, minimum HJHS was 10, maximum was 89 and mean was 40.6 ± 19.8. No statistically significant difference of mean HJHS was found among haemophilia A patients of different severity. (P value = 0.756).

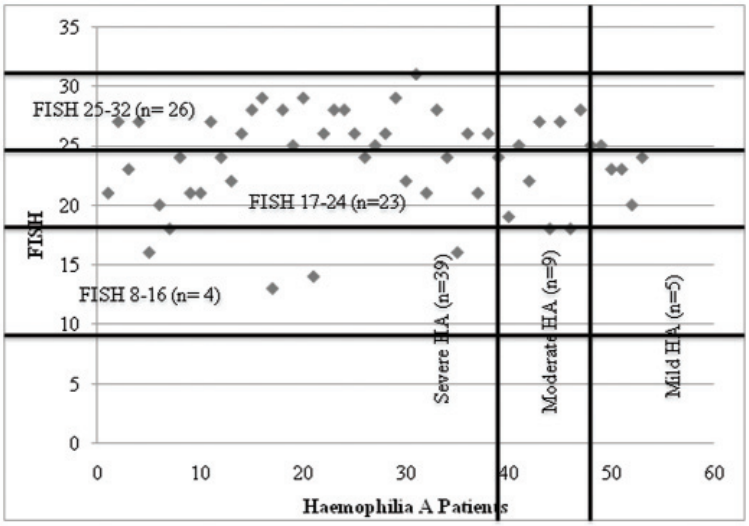
Figure (3). Haemophilia joint health score (HJHS) in patients with haemophilia A (n = 53)



Regarding the functional independence score in 53 patients with haemophilia A, minimum FISH was 13, maximum was 31 and mean was 23.74 ± 4.07 in this study (Figure 4). In patients with mild haemophilia A, minimum FISH was 20, maximum was 25 and mean was 23 ± 1.8. In patients with moderate haemophilia A, minimum was 18, maximum was 28 and mean was 23.2 ± 4. In patients with severe haemophilia A, minimum FISH was 13, maximum was 31 and mean was 23.9 ± 4.3. No statistically significant difference

of mean FISH was found among haemophilia A patients of different severity. (P value = 0.820)

Figure (4). Functional independence score (FISH) in patients with haemophilia A (n = 53)



Discussion

According to the register of the Department of Clinical Haematology, YGH during the year 2016, 82 adult patients with Haemophilia A, 6 adult patients with Haemophilia B, 1 adult patient with factor VII deficiency, 1 adult patient with factor X deficiency, 2 adult patients with factor XII deficiency, 1 adult patient with Von Willebrand Disease (vWD) and 5 adult patients with acquired haemophilia A were registered at the department.[7]

Kar A *et. al* (2007) stated that among 148 Indian patients with haemophilia, 18 patients (12%) were illiterate, 30 patients (20%) had primary level education, 72 (48%) had secondary level education, 24 (16.7%) had graduate level and 4 (2.7%) were postgraduate level education. Out of the 148 patients, 94 patients (65.5%) were able to continue their education, 52 patients (35.1%) had to discontinue their education due to ill health and the remaining 2 patients (1.4%) discontinued their education due to other reasons.[2] The percentage of Myanmar haemophilia patients who discontinued education (45.3%) is found to be slightly higher than that of Indian haemophilia patients. It can be concluded that haemophilia had a significant impact on education of haemophilia A patients in Myanmar as well as in India.

Kar A *et. al* (2007) also stated that among 148 Indian patients with haemophilia A, 47 (31.8%) were in the category over 18 years age group of whom 24 patients (51%) were unemployed. However, the ones who were employed are mostly working in minor jobs with meagre monthly income. Unemployment was found to be significantly more in those patients who had discontinued education.[2] Ferreira AA *et. al* studied 60 patients with haemophilia in a Brazilian blood center and found that 13 patients (27%) were students,

11 patients (22%) were employed formally, 24 patients (49%) had to retire from their job due to illness and the remaining one patient (2%) did not declare the job status.[3] Although unemployment rate among Myanmar haemophilia patients (35.85%) was found to be less than that found in the Indian and Brazilian studies, haemophilia still has a significant impact on employment.

Based on HJHS and FISH findings in this study, it could be seen that haemophilia had a significant impact on the joint health of Myanmar adult haemophilic A patients. Because this study was done in adult haemophilia A patients with established joint damage, the severity of haemophilia was not found to be significantly associated with education, employment and joint health in patients with haemophilia. Other factors such as underlying genetic defects, haemostatic balance of procoagulants and anticoagulants, environmental factors (active or less active life style) could be the other reasons for the non-significant association.

Although no statistically significant association was observed, most of the patients in the study with less joint disability were able to continue their education as well as their employment. The role of prophylaxis treatment with clotting factors may lessen the disability and thus may improve the quality of life of patients with haemophilia A by being able to pursue better education and better employment position. Moreover, the need to counsel young patients on the beneficial effects of exercise was also evident, as disability was significantly associated with the habit of exercise.

Conclusion

Haemophilia A has significant impact on education and employment as well as on joint status and functional status in Myanmar patients. The HJHS and FISH instruments may be extremely useful in the clinical practice although imaging examinations such as magnetic resonance imaging (MRI), are very sensitive to detect early joint damage. The data observed in this study may be valuable for future studies on Myanmar patients with haemophilia A as this is the first documented evidence regarding the impacts of haemophilia on education, employment and joint health in Myanmar patients with haemophilia A. The data also high-lighted the need to improve haemophilia care in Myanmar.

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