

Relationship between socioeconomic status and quality of life in Haemophilia

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Abstract

Introduction: The relationship between quality of life in haemophilia and socioeconomic status of patient has not been well studied. Many of the previous studies were present on health related quality of life but only a few have enlighten the relationship between health related quality of life and socioeconomic status. **Objective:** To find the effect of socioeconomic status on quality of life in Haemophilia patients. **Method:** The study was conducted in S.M.S Medical college from April 2012 to November 2013. We included 88 patients in our study. Socioeconomic status of the patients was assessed by Kuppusswamy scale and evaluation of quality of life was done by WHO SF-36 scale. Comparison of SF 36 and Kuppusswamy scale was done by appropriate statistical methods. **Results:** Out of 88 patients, 80 patients were having Haemophilia Type A and 8 patients were having Haemophilia Type B. Average age of patients was 21 ± 9.9 yrs. Spearman rank order test was done for comparison of socioeconomic status and Physical Component Summary (PCS), Mental Component Summary (MCS) of quality of life. We found a positive correlation between socioeconomic status and quality of life. **Conclusion:** Positive correlation was found between socioeconomic status and physical and mental component of quality of life. As we proceed from poor to upper 1 we found an increase in quality of life in haemophilia patients with best quality of life in upper 1 and worst quality of life in lower group. Availability of free Factor for Haemophiliawill benefit the lower strata patients and help them in improving quality of life.

Keywords: Haemophilia, Quality of life, Socioeconomic status

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Introduction

The impact of socioeconomic status on the quality of life of haemophilia patients has not been sufficiently addressed in previous times. Economically weaker patients had already a disadvantage of lack of school education and professional career, and added on that the burden of treatment of haemophilia is immense on the patients. Subsidised treatment for Factor in haemophilia is of limited availability which causes a major burden on the pocket of haemophilia patients. Haemophilia is known to affect Health services through repeated admission in the hospital for factor management. Haemophilia A affects every 5000 male births, and haemophilia B affects 1 in every 30000 male births[1].

Haemophilia A and B are single gene disorders, occurring due to mutation in coagulation viii gene (haemophilia A) and coagulation factor is gene (Haemophilia B) due to deficiencies in the synthesis of factor viii and is, patients of haemophilia have tendencies for haemorrhage[2]. Classification of haemophilia is based on the severity of factor deficiency severe (factor <1), moderate (factor 1-5) and mild (factor 5-40) percent of normal clotting factor levels. Haemophilia A constitutes majority of hemorrhagic episodes around 70 percent. Haemophilia patients are treated with replacement therapy with either factor viii for haemophilia A and Factor ix for haemophilia B, or either with cryoprecipitate or fresh frozen plasma[3,4,5,6]. Joint bleeding, persistent pain and other clinical manifestations can have great impact on quality of life during the course of disease[7]. The SF36 is very commonly used in calculating HRQoL[8].

Socioeconomic status of patients is measured using Kuppusswamy score[9], which divides the population into five classes.

Methodology

The study was performed in the department of Physical Medicine and Rehabilitation at S.M.S Medical college and hospital, Jaipur. We conducted this study from April 2012 to November 2013 after taking permission from the institute ethics committee and research review board. This is an observational hospital based study performed on patients of Haemophilia A and B.

Inclusion Criteria

- Patients age > 13 yrs
- Willingness to participate in the study
- Mild, Moderate, Severe Hemophilia patients

Exclusion Criteria

- Patients age < 13 yrs
- Unwillingness for participation and other bleeding disorder like Von willebrand disease

Patient aged 14 to 45 were included in the study, who are attending department of physical medicine and rehabilitation

All patients with Haemophilia were assessed, screened and informed about the study's kind and purpose. Patients who gave their informed consent for participation in the study were involved in this study. Patient demographic data was noted and health related quality of life was assessed using SF36 score and socioeconomic data was assessed using Kuppusswamy score. SF-36[8] questionnaire determines quality of life in eight different dimensions of health i.e. physical functioning, social functioning, physical and mental role limitations, mental health, energy/vitality, pain and general health perception. Each dimension described in scale was transformed on to a scale from 0 (worst health) to 100 (best score). Results from SF-36 can also be reported as a physical component scale (PCS) and mental component scale (MCS).

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Kuppuswamy scale[9] was used for socioeconomic status which consist of five socioeconomic class i.e upper I, upper middle II, lower middle III, upper lower IV, lower.

Statistical methods

All haemophilia patients were analysed on the scales as mentioned previously. All patients were categorised according to Kuppuswamy scale. Spearman rank order test was used to find the correlation/ association of socioeconomic status and different domain of quality of life i.e PCS and MCS. Data was expressed as mean, standard deviation or percentage as appropriate. Student t test for unpaired data was used. Association between Kuppuswamy score and SF-36 scale was evaluated with Spearman rank order test. Two tailed P values <.05

were considered statistically significant. All analyses were performed using IBM SPSS software, version 20.0.

Results

A total of 88 diagnosed cases of Haemophilia aged between 14yrs to 45 yrs attending the department of physical medicine and rehabilitation were enrolled in the study.

Out of 88 patients 91% cases were diagnosed as haemophilia A while 9% were diagnosed as haemophilia B. Mean age of patient was 21± 9.9 yrs. The study group comprised only males indicating the sex linked recessive inheritance of the haemophilia.

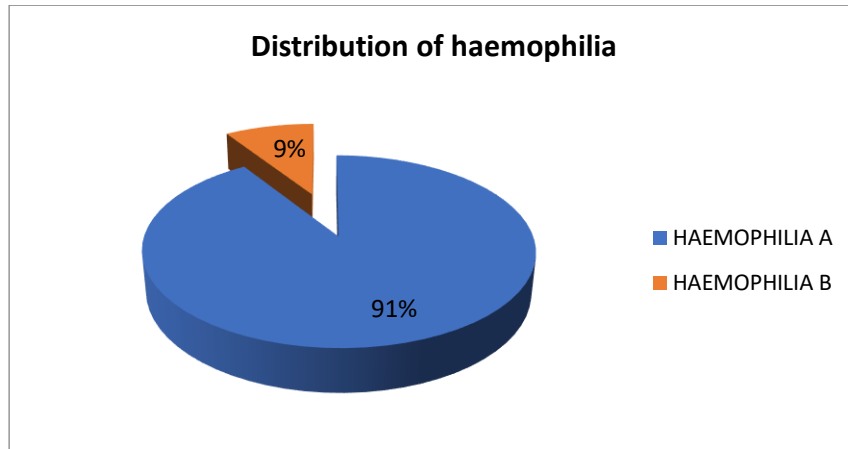


Fig 1: Distribution of Haemophilia

In our study, nearly 61.25% of the Haemophilia A population belonged to severe haemophilia. Whereas 33.75% of the patient population belonged to moderate and only 5% of the population belonged to mild haemophilia.

Table1: Factor VIII levels in haemophilia A

Severity	Haemophilia-A	Percentage
Mild	4	5
Moderate	27	33.75
Severe	49	61.25
Total	80	

In our study, nearly 61.25% of the Haemophilia A population belonged to severe haemophilia. Whereas 33.75% of the patient population belonged to moderate and only 5% of the population belonged to mild haemophilia.

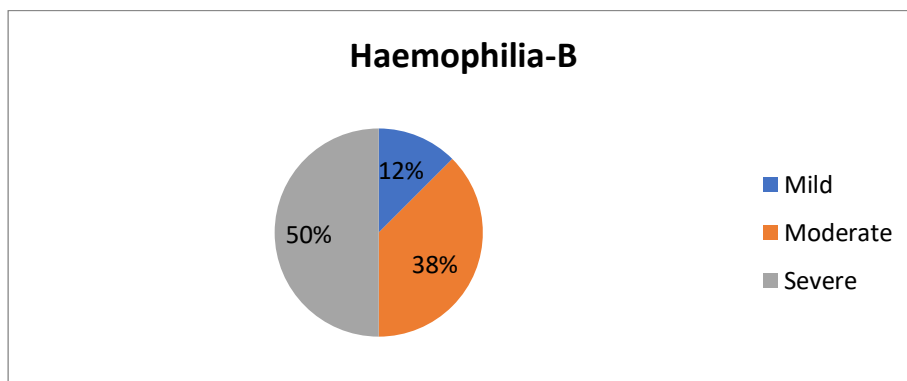


Fig 2: Factor IX levels in Haemophilia B

Table 2: Factor IX levels in Haemophilia B

Severity	Haemophilia-B	Percentage
Mild	1	12.5
Moderate	3	37.5
Severe	4	50
Total	8	

In our study, out of total 8 cases of Haemophilia B, 50% cases had severe haemophilia while 37.5% of the patients had moderate haemophilia and 12.5% of the patient had mild haemophilia

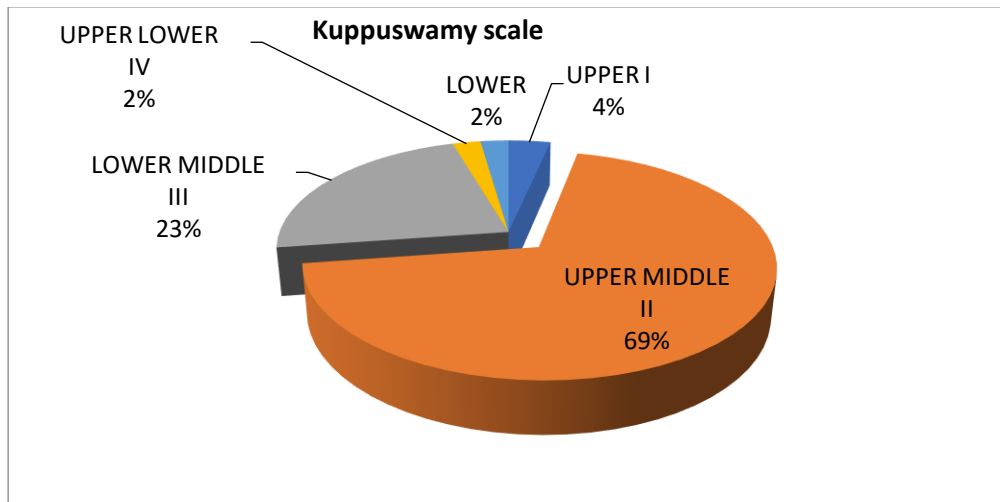


Fig 3: Socioeconomic status of haemophilia patients

Table 3: Socioeconomic status of haemophilia patients

Kuppuswami Scale- Socio Economic class	NUMBER	PERCENTAGE
UPPER I	3	3.4
UPPER MIDDLE II	61	69.4
LOWER MIDDLE III	20	22.72
UPPER LOWER IV	2	2.2
LOWER	2	2.2
TOTAL	88	

In our study, haemophilia patients were divided in different socioeconomic class by using Kuppuswamy scale in this we found 2.2% of the patients in lower socioeconomic status, 2.2% in the upper lower status, 22.72% cases in the lower middle III and 69.4% cases lie in upper middle II, and only 3.4% of the cases belongs to upper I group. From this we can say that the maximum haemophilic patients belong to upper middle II group.

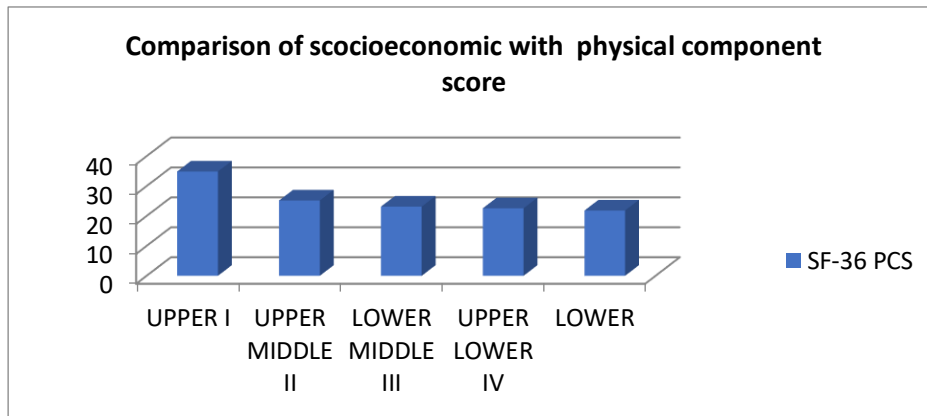


Fig 4: Comparison of socioeconomic with physical component score
 Table 4: Comparison of socioeconomic with physical component score

Kuppuswami Scale- Socio Economic class	SF-36 PCS
UPPER I	34.87
UPPER MIDDLE II	25.17
LOWER MIDDLE III	23.12
UPPER LOWER IV	22.57
LOWER	21.83

In our study, p value was significant on spearman rank order test, in the comparison of socioeconomic status and physical component of quality of life. We found a positive correlation between socioeconomic status and the quality of life as we proceed from poor to upper I we found an increase in the quality of life in haemophilia patients with best quality of life in upper I and worst quality of life in lower group.

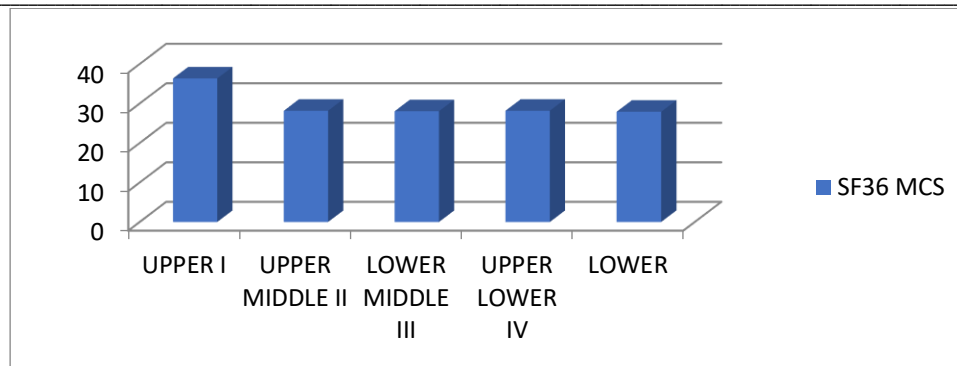


Fig 5: Comparison of socioeconomic with Physical component score

Table 5: Comparison of socioeconomic with Mental component score

Kuppuswami Scale- Socio Economic class	SF36 MCS
UPPER I	36.33
UPPER MIDDLE II	28.15
LOWER MIDDLE III	28.03
UPPER LOWER IV	28.16
LOWER	27.9

In our study, p value was significant on spearman rank order test, in the comparison of socioeconomic status and mental component of quality of life. We found a positive correlation between socioeconomic status and the quality of life as we proceed from poor to upper I we found an increase in the quality of life in haemophilia patients with best quality of life in upper I and worst quality of life in lower group.

Discussion

In our study we compared the socioeconomic status of the patient with quality of life, for socioeconomic status Kuppuswamy score was used and for quality of life SF-36 score. Kuppuswamy divided the socioeconomic status into 5 groups i.e. upper I, upper middle II, lower middle III, upper lower IV and lower. We found that the lower group has significantly lower quality of life as compared to the upper I group. We also found a positive correlation between socioeconomic status and the quality of life as we proceed from poor to upper I, we found an increase in the quality of life in haemophilia patients with best quality of life in upper I and worst quality of life in lower group. In one study of relationship between haemophilia and social status done by Holstein et al[10] they explore the impact of haemophilia and its treatment on social status but in our study we tried to explore the effect of socioeconomic status of individual on quality of life, other Studies[11,12,13] also done with the same objective to explore the impact of haemophilia on social status but to best of our knowledge no study till date was performed to find the impact of socioeconomic status on quality of life this is the first of its kind of study .

Conclusion

The impact of socioeconomic status on haemophilia has not been well studied, although many research work was done to find the quality of life in patients with haemophilia on different aspects of life component i.e physical component and mental component .Low socioeconomic status patients had many disadvantages like high rate of disability, unemployment and lack of access to essential services, whereas such disadvantages were not present in the higher socioeconomic group. In the treatment part of haemophilia issues of equity will have to be kept in mind because many patients are from rural or remote areas and have less accessibility to the services of tertiary health care centre which is available in cities. The prevention of haemophilia is also needed to be addressed, there is very less or no data available on the socioeconomic status, social cost of haemophilia, we tried to explore this and found that there is a need of

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uniform free factor availability in the country to haemophilia patients will help a lot the weaker section of patients with haemophilia. To our knowledge, this is the first study in India which has documented the effect of socioeconomic status on quality of life of haemophilia patients in India. But still a large number of multicentric trials and studies are required to observe the effect of socioeconomic status on quality of life of haemophilia on long term.

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