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Quick Response Code:

Website: www.jehp.net
DOI: 10.4103/jehp.jehp_249_19

Health-related quality of life of hemophilics and its possible correlates: A perspective in health promotion and disability prevention

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Abstract:

BACKGROUND: Clinical evaluations are not sufficient to adequately characterize the morbidity associated with hemophilia. Quality of life (QoL) of hemophilics and associated factors is not well explored in Indian research. The present study aimed to measure the QoL in hemophilics and its association with socio-demographic characteristics and other characteristics.

MATERIALS AND METHODS: A cross-sectional study was conducted during June–November 2018. Two hundred and one hemophilics (age ≥ 4 years) were interviewed with a pre-tested schedule for sociodemographic and other relevant variables. QoL was measured by Haemo-QoL questionnaire for different pediatric age groups and Haem-A-QoL questionnaire for adults and assigned health-related QoL scores. Score achieved in each dimension as well as total scores were transformed on scales ranging from 0 to 100, high values indicate high impairment of QoL. Hemophilic arthropathy was assessed using the World Federation of Hemophilia Joint Scores. One-way ANOVA, independent *t*-test, Kruskal–Wallis test, and Spearman correlation analyses were performed using SPSS version 16.

RESULTS: Mean Haemo-QoL scores for 4–7 years, 8–12 years, 13–16 years, and >16 years were 43.92 ± 8.09 , 37.37 ± 8.62 , 32.79 ± 6.66 , and 45.92 ± 6.30 , respectively. Significant difference was noted for QoL scores across different age groups, grades of severity, educational, occupational categories, socioeconomic status classes, marital status, and presence or absence of target joint. Total QoL scores, as well as scores in some of the dimensions, showed a significant positive correlation with the World Federation of Hemophilia joint scores by Spearman correlation analysis.

CONCLUSIONS: Improvement of the joint health status by regular physiotherapy is needed to improve the QoL of hemophilics.

Keywords:

Haemo-quality of life score, health-related quality of life, hemophilics, target joint

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Received: 04-05-2019
Accepted: 23-05-2019

Introduction

The World Health Organization defined quality of life (QoL) as “individuals’ perceptions of their position in life in the context of culture and value systems in which they live, and in relation to their goals, expectations, standards, and concerns”^[1] “Health-related quality

of life (HRQoL) is a multidimensional construct pertaining to the physical, emotional, mental, social, and behavioral components of wellbeing and function as perceived by the patients and/or observers”^[2] Not only disease and its treatment, but HRQoL is also influenced by personal characteristics such as coping or internal locus of control as well as by living conditions and socioeconomic status.

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How to cite this article: Das S, Roy RN, Das DK, Chakraborty A, Mondal R. Health-related quality of life of hemophilics and its possible correlates: A perspective in health promotion and disability prevention. *J Edu Health Promot* 2019;8:257.

Hemophilia is a life-long coagulopathy, which is characterized by spontaneous, posttraumatic, and postsurgery bleeding. Bleeding in the joints leads to pain, severe joint damage, disability, and dramatic impairment of the HRQoL. Hemophilia A and B are inherited as X-linked recessive bleeding disorders.

Studies on HRQoL are based on the increasingly evident need for medical care not to be limited to preventing death, but to focus on the value of health instead.^[3] In case of hemophilia, the major issues are the restrictions on physical activities, concern about bleeding that might be life-threatening, development of arthropathy, need for orthopedic procedures, and infectious diseases transmitted by blood or blood products much less frequently.^[4,5]

Modern management has been successful in hemophilia in improving the clinical symptoms, orthopedic status, and the survival of patients. These aims have broadened to include the more comprehensive wellbeing and HRQoL of patients with hemophilia more recently.^[6] In the last decade, QoL assessment has become more utilized in the field of hemophilia research, allowing the assessment of patient's perception of the overall effect of hemophilia care. As the clinical evaluations may not be sufficient to adequately characterize the morbidity associated with hemophilia,^[7,8] the present study aimed to measure HRQoL and to explore its association with sociodemographic factors, and joint health status of the study participants.

Materials and Methods

A cross-sectional study was conducted during June–November 2018 in two randomly selected hemophilia society chapters (Durgapur and Kharagpur chapters) out of four chapters in West Bengal. All hemophilics aged 4 years and above, registered in the aforesaid two chapters at least for 6 months before actual conduction of study were included. Those who were absent during data collection due to any bleeding episodes or any other reasons during that time, and those who were unwilling to take part in the study were excluded. There was a total of 250 registered hemophilics in the selected chapters; applying eligibility criteria 49 were excluded; thus, a total of 201 hemophilics were studied.

Study tools used were a pretested schedule containing questions related to sociodemographic characteristics and other descriptive variables related to hemophilia; Haemo-QoL questionnaire which is a QoL assessment instrument for children and adolescents with hemophilia^[9] designed for three age groups 4–7 years, 8–12 years, 13–16 years; Haem-A-QoL questionnaire which is a QoL assessment instrument for adult patients^[10-12] living

with hemophilia having a total of 46 items divided into 10 dimensions. For both of the QoL assessment tools, the calculation of the scores is performed by transforming to a scale from 0 to 100 to allow comparison between answers of different age groups. High values indicate high impairment of the HRQoL.

Study tool used for physical examination was the World Federation of Hemophilia (WFH) joint score which is in practice used for assessment of hemophilic arthropathy. A normal joint is scaled as zero. Joint abnormalities entail additive positive scores; the highest score achievable for a single joint is 12 for ankle or knee and ten for the elbow.

The study subjects were interviewed for basic descriptive variables. All of the 4–7-year-old individuals were interviewed with the help of Haemo-QoL questionnaire for 4–7 years age group. For 8–12 years, 13–16 years old individuals Haemo-QoL questionnaire and for adults Haem-A-QoL questionnaire were self-administered. Physical examination of the individuals was performed using the WFH joint scores with the help of a trained physiotherapist. Goniometer instrument was used for measuring axial deformity of the joints. Any medical record, if available, was also reviewed. Members were briefed about the purpose and nature of the study. Consent and assent were obtained before data collection. The study had approval from Institutional Ethics Committee.

One-way ANOVA, independent *t*-test, Kruskal–Wallis test, and Spearman correlation analyses were performed using Statistical Package for Social Sciences (SPSS) 16.0 version software. (SPSS, Inc., Chicago, IL, USA).

Results

Health-related quality of life of hemophilics

A total of 201 hemophilics were studied. HRQoL was measured using transformed HRQoL scores for all age groups (total scores as well as scores in different dimensions of QoL). Mean total QoL scores for all study subjects was 41.11 ± 8.9 [Table 1]. Nonsignificant result of Kolmogorov–Smirnov test revealed that total transformed QoL scores were distributed normally.

Sociodemographic profile and different health conditions related to hemophilia including assessment of joint health status using the World Federation of Hemophilia joint scores

Among 201 study individuals, 100% were male. As it is an X-linked recessive disorder, occurrence among female is very rare. 79.6% and 20.4% were Hindu and Muslim, respectively. 61.7%, 13.9%, 4.5%, and 19.9% study individuals belonged to General, SC, ST, and OBC category, respectively. 61.2% and 38.8% study individuals

Table 1: Transformed Scale Score of Haemo-quality of life, Haem-A-quality of life scores for different age groups

Dimensions of HRQoL	Mean±SD				
	4-7 years (n=29)	8-12 years (n=37)	13-16 years (n=45)	>16 years (n=90)	All patients (n=201)
Physical health	12.50* (12.50-31.25)	21.43* (14.28-75.00)	25.00* (16.07-60.71)	65.00* (30.00-70.00)	37.50 *(17.86-67.87)
Feelings	50±19.9	36.48±9.5	28.68±12.8	56.04±17.7	45.44±19.5
View	43.10±21.0	31.98±12.4	21.88±10.7	42.05±15.5	35.83±17.1
Family	54.57±15.6	52.30±13.1	37.66±8.7	-	46.96±14.4
Friend	43.10±32.0	46.28±14.9	37.78±16.0	-	42.00±21.2
Perceived support	-	42.23±19.4	38.47±15.2	-	40.17±17.2
Others	44.83±18.1	28.72±7.7	23.43±12.7	-	30.78±15.6
Sports and school/leisure	42.53±17.0	47.46±15.0	44.69±10.9	60.11±12.4	51.79±15.3
Dealing	-	29.15±12.9	29.76±11.7	24.90±11.6	27.09±12.1
Treatment	46.55±18.6	22.20±10.5	25.24±9.5	52.74±9.6	40.07±17.8
Future	-	-	30.14±19.2	56.72±16.4	47.86±21.4
Relationship/partnership	-	-	36.94±17.3	32.31±15.9	33.86±16.5
Work/school	-	-	-	43.82±18.5	43.82±18.5
Family planning	-	-	-	37.01±18.6	37.01±18.6
Total	43.92±8.1	37.37±8.6	32.79±6.7	45.92±6.3	41.11±8.9

*Median (IQR) values were given as data were not distributed normally. HRQoL=Health-related quality of life, SD=Standard deviation, IQR=Inter quartile range

belonged to nuclear and joint families, respectively. 86.1% and 13.9% of the study individuals were deficient in factor VIII and factor IX, respectively. Religion ($t[199] = 1.033$, $P = 0.303$), caste ($F [3,197] = 1.409$, $P = 0.241$), type of family ($t[199] = 1.760$, $P = 0.08$) and factor deficiency ($t[199] = 0.205$, $P = 0.838$) were not significantly associated with QoL scores. Whereas age, educational status, occupational status, socioeconomic status, marital status, presence of any target joint, and grades of severity of hemophilia were found to be significantly associated with QoL scores [Table 2]. Tukey HSD *post hoc* test revealed that mean QoL scores of married study individuals were significantly different from that of individuals who were unmarried below legal age of marriage ($P < 0.05$). Again, mean QoL scores of individuals who were unmarried at or above legal age of marriage were significantly different from that of individuals who were unmarried below legal age of marriage ($P < 0.05$). The significant difference of mean QoL scores was found between mild and severe ($P < 0.05$), moderate and severe ($P = 0.000$) grades of severity of hemophilia. However, no significant difference of QoL scores was found to exist between mild and moderate grades of severity of hemophilia ($P = 0.979$). Socio-economic status was measured by Modified BG Prasad Scale (CPI [IW]: 301 [September 2018]).

The median number of bleeds per month was two. Average number of factor transfusions required per month was 2.44 ± 1.05 (1 factor transfusion = 1000 IU of factor transfusion). One hundred and ten, i.e., 54.7% of the study individuals were having target joints, i.e., the occurrence of three or more hemarthroses in the same joint in the 6 months preceding the study. recurrent joint bleeding in the same joint (weight-bearing joints such as knee, elbows, and ankle) results in progressive joint damage and development of hemophilic arthropathy

over prolonged periods, characterized by synovial hypertrophy, cartilage damage, loss of joint space, and bony changes.

Median age at first bleed was 36.00 (9.00–45.00) months, and median age at diagnosis was 36.00 (13.50–48.00) months for all study individuals. Maximum number of study individuals were with O + blood group (41.2%). Maximum number of study individuals had joint bleed as their first bleed after birth (34.8%).

Assessment of joint health status by the World Federation of Hemophilia joint scores

The assessment of joint health status of the study individuals has been summarized in Table 3. Out of total 201 study individuals, 85.6% had no axial deformity, 13.4% had Grade I axial deformity, and only 1.0% had Grade II axial deformity of ankle joint. Significant result of Kolmogorov–Smirnov test revealed that total WFH joint scores were not distributed normally.

Significant difference ($H(3) = 29.375$, $P < 0.01$) was found for total WFH joint scores across different age groups as well as across different grades of severity of hemophilia ($H(2) = 165.56$, $P < 0.01$) in Kruskal–Wallis test. Median \pm interquartile range of total WFH joint scores in different age groups is shown in Figure 1.

Association of quality of life scores (total transformed scores as well as transformed scores in different dimensions in different age groups) with World Federation of Hemophilia joint scores

“Physical health” in all four age groups, “View” in 8–12 years and 13–16 years, “Perceived support” in 8–12 years, “Others” in 13–16 years, “Dealing” in 8–12 years, and “Future” in 13–16 years dimension

Table 2: Different sociodemographic and other variables and their association with total transformed quality of life scores (n=201)

Sociodemographic and other variables	Mean±SD		
	n (%)	Haemo-QoL and Haem-A-QoL total transformed score	P/significance F (degree of freedom)
Age (years)			
4-7	29 (14.4)	43.92±8.09	F (3, 197)=39.075, P<0.05*
8-12	37 (18.4)	37.37±8.62	
13-16	45 (22.4)	32.79±6.66	
>16	90 (44.8)	45.92±6.30	
Educational status			
Preschool/illiterate/non-formal literate	29 (14.4)	45.25±8.53	F (5, 195)=10.941, P<0.05*
Primary	17 (8.5)	39.27±7.93	
Middle	33 (16.4)	36.42±8.51	
Secondary	44 (21.9)	36.64±8.47	
Higher secondary	28 (13.9)	41.32±8.43	
Graduation and above	50 (24.9)	46.27±6.51	
Occupational status			
Civil servant	9 (4.5)	47.59±6.26	F (5, 195)=7.417, P<0.05*
Student	124 (61.7)	38.41±8.96	
Unemployed	25 (12.4)	45.48±5.93	
Business	14 (7.0)	44.85±6.06	
Not yet started school	24 (11.9)	44.16±8.56	
Others	5 (2.5)	49.69±6.95	
Socioeconomic status			
Upper	35 (17.4)	45.38±6.92	F (4, 196)=4.255, P=0.003*
Upper middle	45 (22.4)	39.25±8.54	
Middle	42 (20.9)	39.04±8.95	
Lower middle	55 (27.4)	40.11±9.73	
Lower	24 (11.9)	44.31±7.89	
Marital status			
Married	23 (11.4)	46.42±6.92	F (3, 197)=10.63, P<0.05*
Separated/divorced/widowed	10 (5.0)	45.73±3.84	
Unmarried (≥ legal age of marriage)	31 (15.4)	45.71±6.47	
Unmarried (below legal age of marriage)	137 (68.2)	38.85±9.10	
Presence of any target joint			
Yes	110 (54.7)	44.41±8.08	t (199)=6.290, P<0.05*
No	91 (45.3)	37.13±8.28	
Grades of severity of hemophilia [†]			
Mild	43 (21.4)	37.17±9.40	F (2, 198)=28.817, P<0.05*
Moderate	60 (29.9)	36.86±7.57	
Severe	98 (48.7)	45.45±7.35	

[†]Mild=Level of factor VIII/IX between 5% and 30%, Moderate=Factor level between 1% and 5%, Severe=Level of factor VIII/IX <1%. QoL=Quality of life, SD=Standard deviation

scores (transformed) showed significant positive correlation with WFH joint scores in Spearman correlation analysis. Total Transformed QoL scores of 8–12 years ($\rho = 0.852, P < 0.05$), 13–16 years ($\rho = 0.822, P < 0.05$), and >16 years ($\rho = 0.436, P < 0.05$) also showed significant positive correlation with WFH joint scores.

Discussion

QoL is defined as well-being and functioning in physical, social, and emotional domains. Hence, it allows the augmentation of traditional clinical indicators of health

with data gathered from the patient’s perspective. The current study tried to measure the QoL of the hemophiliacs registered in the Hemophilia Society Durgapur Chapter and Kharagpur Chapter, West Bengal as well as its association with various factors. The result from the present study might have similarities and differences with the observations from the other related studies available in the literature. Appropriate interpretations of such evidence would help identifying measures for addressing the issues.

Strikingly, it was found in a Turkish study^[13] by Mercan *et al.* that age at diagnosis was quite late, especially in

adult patients, which was 8.5 ± 10.4 years and only 32.3% were diagnosed before 24 months. In children, the age at diagnosis was 21.7 ± 2.4 months, and 80% were diagnosed before 24 months of age. However, in the present study, it was found that average age at diagnosis is 31.86 ± 19.74 months for all study subjects. In the West European study, 50.3% of all study subjects had target joints (38.9% in the age group of 4–7 years, and 61% in the age group of >16 years) and in the aforesaid Turkish study, 82% of children and 60% of the adults had target joints. Number of target joints is expected to increase with age. In a Brazilian study^[14] by Ferreira *et al.* in the present study, it was found that 69.2% of the

study individuals are having target joints. It was also found that number of target joint increases as the age advances. Many patients with severe phenotype who could not be treated might have already died during circumcision or other life-threatening bleeding episode before reaching adulthood. Mainly adult patients with higher motivation for training and higher compliance to treatment volunteered for the present study.

The number of mean factor infusion per month was 3.2 ± 2.6 for patients on-demand treatment in West European study, and they experienced 1.1 ± 1.6 bleeding events per month. In the aforesaid Turkish study, the number of bleeding events per month was approximately 2.05 ± 0.65 according to the reports of the parents or patients, and they had 5.5 ± 4.4 factor infusions. High number of target joints caused frequent bleeding episodes and more factor consumption. In the present study, it was found that median number of bleeds per month is two. Average number of factor transfusions required per month is 2.44 ± 1.05 .

Total mean Haemo-QoL scores were about 40 in children whereas it was about only 20 in the West European study. In the 4–7-year-old group, scores on relations with family and treatment were more impaired compared to the older children and adolescents. They generally had complaints about the restrictions from their family to prevent trauma, and they refused factor transfusions. Adults had more impaired scores in “sport and leisure time,” “future,” and in “treatment.” The aim of including adult patients to the study was to evaluate chronological

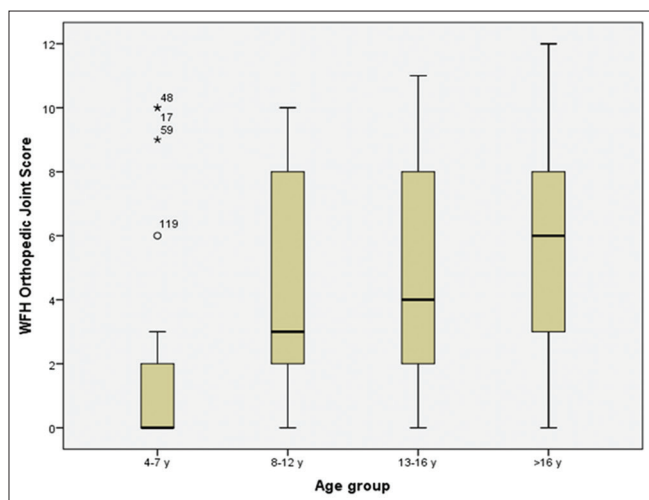


Figure 1: Box and Whisker Plot diagram showing the distribution of the World Federation of Hemophilia scores in different age groups

Table 3: Assessment of joint health status of the study subjects using the World Federation of Hemophilia joint scores

Physical finding	4-7 years (n=29), n (%)	8-12 years (n=37), n (%)	13-16 years (n=45), n (%)	>16 years (n=90), n (%)	All patients (n=201), n (%)
Swelling					
None	15 (51.7)	9 (24.3)	8 (17.8)	15 (16.7)	47 (23.4)
Present	14 (48.3)	28 (75.7)	37 (82.2)	75 (83.3)	154 (76.6)
Muscle atrophy					
None	27 (93.1)	35 (94.6)	39 (86.7)	68 (75.6)	169 (84.1)
Present	2 (6.9)	2 (5.4)	6 (13.3)	22 (24.4)	32 (15.9)
Crepitus on motion					
None	25 (86.2)	24 (64.9)	24 (53.3)	47 (52.2)	120 (59.7)
Present	4 (13.8)	13 (35.1)	21 (46.7)	43 (47.8)	81 (40.3)
Range of motion (°)					
Loss of <10	25 (86.2)	22 (59.5)	21 (46.7)	25 (27.8)	93 (46.3)
Loss of 10-33	0 (0)	2 (5.4)	3 (6.6)	35 (38.9)	40 (19.9)
Loss of >33	4 (13.8)	13 (35.1)	21 (46.7)	30 (33.3)	68 (33.8)
Flexion contracture (°)					
≤15	25 (86.2)	27 (73.0)	26 (57.8)	47 (52.2)	125 (62.2)
>15	4 (13.8)	10 (27.0)	19 (42.2)	43 (47.8)	76 (37.8)
Axial deformity knee					
No deformity	23 (79.3)	22 (59.5)	21 (46.7)	30 (33.3)	96 (47.8)
Grade I	4 (13.8)	13 (35.1)	18 (40.0)	42 (46.7)	77 (38.3)
Grade II	2 (6.9)	2 (5.4)	6 (13.3)	18 (20.0)	28 (13.9)

improvement in hemophilia care as well as increasing interaction to contribute their education and training in hemophilia.

WFH joint score was found to be more impaired in adult patients (5.60 ± 3.12) compared to other age groups in the present study. Adult patients who were older than 18 years had more impaired QoL, mainly due to more impaired joint health status compared to children and adolescents due to less access to hematologist and factor concentrate in the past. Although a positive correlation of joint scores with especially physical health and sports and school/leisure times of Haemo-QoL was expected, only physical health dimension of adults showed such a correlation. "Physical health" in all four age groups, "View" in 8–12 years and 13–16 years, "Perceived support" in 8–12 years, "Others" in 13–16 years, "Dealing" in 8–12 years, and "Future" in 13–16 years dimension scores (transformed) showed significant positive correlation with WFH joint scores. The results were quite similar with that of the Turkish study.

Due to insecurities of getting exposed, the possibility of hiding fact/truth cannot be denied and QoL of hemophilics < 4 years age could not be assessed because of the unavailability of tools. These are some of the limitations of the study. Furthermore, result from a small sample of population in the present study may not be applicable on a larger population, so there is a need for study with a large sample for generalization.

Conclusions

QoL scores were found to be positively correlated with WFH joint scores. Thus, improvement of the joint health status by regular physiotherapy is needed to improve the QoL of hemophilics.

Acknowledgment

The researchers sincerely acknowledge the contribution, support, and cooperation of the governing bodies of the hemophilia societies along with the study participants in this research work. The support given by the trained physiotherapists for certain aspects of physical examination of the study participants is also worth mentioning. The researchers would also like to express their gratitude for the Principal of Burdwan Medical College for her immense support.

Financial support and sponsorship

Nil.

Conflicts of interest

There are no conflicts of interest.

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