INTERNATIONAL JOURNAL OF HEALTH & MEDICAL RESEARCH

ISSN(print): 2833-213X, ISSN(online): 2833-2148

Volume 05 Issue 07 July 2026

DOI : 10.58806/ijhmr.2026.v5i7n09

Page No. 635-639

A Study to Assess the Quality of Life among Hemophilic Children at Selected Hospital, Salem.

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ABSTRACT: A study was done to assess the Quality of Life among hemophilic children at selected hospital,Salem with the objectives to assess the quality of life among hemophilic children and to find out the association between quality of life of hemophilic children with selected demographic variables.Non experimental survey research design was used to conduct the study. By convenient sampling technique 30 haemophilic children taking treatment at OPD for haemophilia were included as samples.Structured questionnaire was used to assess demographic variables & clinical characteristic of haemophilic children. Rating scale was used to assess the quality of life. Quality of life was assessed and rated as poor, average and good. Association was assesed between demographic variables and Quality of life. The study results reported that 22 (73.3%) children had good quality of life, 8 (26.6%) children had average quality of life and there were no children with poor quality of life with haemophilia. Also there was no association found between Quality of Life with deographic and Clinical Variables.

KEY WORDS: Hemophilic Children, Quality of Life .

INTRODUCTION

Haemophilia is a congenital disorder that impact mostly male child. It caused by clotting factor gene mutation or X chromosome, which result in lack of factor VIII or IX in haemophilia A or B. Spontaneous bruising, mucosal and joint bleeding, epistaxis and severe bleeding events like intracranial haemorrhage are common symptoms. Repeated joint bleeding results in severe joint damage and pain resulting in bleeding. [1,2]

Hemophilia A is a congenital life-threatening disorder caused by an inherited deficiency of factor VIII . It is characterized by spontaneous and post-traumatic bleeding events into the joints, muscles, and soft tissues, which can lead to disability. The challenges experienced by children and adolescents with hemophilia A can seriously affect their quality of life (QoL) in a wide range of health, physical, social, and educational settings. [5]

Parental restriction of the child's or adolescent's activities to prevent trauma, frequent absences from school due to repeated bleeding episodes, and the accompanying pain or discomfort associated with a bleeding episode are factors that limit or interfere with physical functioning, social and intellectual development, and academic performance . Children and adolescents with hemophilia also experience difficulties that include frequent hospital visits, frequent injections, and inability to fully participate in daily activities .[5]

The cross sectional study, Children with hemophilia aged 4 to 12 years, and their parents who were attending the Pediatric Hematology Clinic of the Advanced Pediatric Centre, PGIMER, Chandigarh, between July 2009 and June 2010 were included in the study. The study included 51 children with 10 children in 4-7 years age group and 41 children in 8-12 years age group and their parents. Perceived impact on family (77.3±14.7), poor physical health (62.9±29.8), sports and school (53.8±22.8) had the highest negative impact on QoL. The study concluded that the Quality of life was poor both among children affected with hemophilia and their parents. Perceived impact on family, poor physical health and inability to participate in school/sports activities are the major contributors to poor QoL. Support from family, friends, and others is vital in maintaining QoL[3].

Another cross sectional study was carried out with the objective to determine the health related quality of life (HRQoL) of hemophiliac children using the Haemo-QoL questionnaire. A total of 89 hemophiliac children (4–16 years) were enrolled. Among these, 76 (85.39%) children had hemophilia A, while 13 (14.61%) had hemophilia B. The mean Haemo-QoL scores were 52.27 ± 11.72, 47.46 ± 11.68 and 47.75 ± 9.41 in children aged 4–7 years, 8–12 years and 13–16 years, respectively. The family domain had the greatest impairment in HRQoL in the 4–7 years old and 8–12 years old age groups, whereas in the 13–16 years old children, the sports and school domains were the worst affected. A comparison of the Haemo-QoL based on presence or absence of inhibitors revealed statistically significant difference among children aged 13–16 years. Presence of target joints in children aged 8–12 years & 13–16 years was significantly associated with lower health related quality of life. Similarly, a comparison of the

Haemo-QoL according to the severity of hemophilia revealed greater impairment among severe hemophilia patients in the 8–12 years and 13–16 years age groups. So to conclude, severity of disease as well presence of target joints and inhibitors had a negative impact on HRQoL. The major contributors to poor HRQoL are physical health, perceived impact on family and inability to participate in school/sports activities.[6]

The hospital-based cross sectional study was conducted among 49 children , aged from 4-12 years, with factor VIII/ IX deficiency who presented in the Paediatric ward of the study Institution for factor transfusion, were included in the study. The study population was divided into two groups with children aged 0-4 years (group I) and children aged 8-12 years (group II). A detailed clinical history and Consent was obtained from the accompanying parent/guardian, and QoL was measured using the Haemophilia QoL (Haemo-QoL) questionnaire. Results of the study revealed that, haemophilia A was more common than haemophilia B. All patients who attended the paediatric ward for factor transfusion were males, with a mean age of 8.37±2.56 years. The mean overall scores on the Haemo-QoL for the age groups 4-7 years and 8-12 years were 41.92±17.95 and 51.84±16.36, respectively. The highest impairment was in the physical health, school and sports, and family dimensions of QoL. The QoL is poor among children in both age groups. The current study also showed that as age advances, the QoL of haemophilia patients becomes poorer.[2,7]

STATEMENT OF THE PROBLEM

A study to assess the Quality of Life among hemophilic children at selected hospital,Salem..

OBJECTIVES OF THE STUDY:

1.To assess the quality of life among hemophilic children.
2.To find out the association between quality of life of hemophilic children with selected demographic variables.

HYPOTHESIS

H1: There is a significant association between quality of life of hemophilic children with selected demographic variables at $p \leq 0.05$ level.

RESEARCH METHODOLOGY: (MATERIALS and METHODS)

Quantitative descriptive research approach with Non experimental survey research design was used to conduct the study. By convenient sampling technique 30 Haemophilic children taking treatment at OPD for haemophilia in the selected hospital for the past 1 year between the age group of 0 -18 years.

TOOLS USED FOR THE STUDY

Structured questionnaire was used to assess demographic variables & clinical characteristic of Haemophilic children's. Rating scale was used to assess the quality of life. Demographic variables include age of child, sex, residence, class studying and religion. Clinical characteristic includes haemophilia type, time since diagnosis, type of bleeding events, involvement of joints heavy bleeding episodes in the last year, episodes of hospitalization, episodes of visiting emergency department, family history of haemophilia, current haemophilia treatment and treatment approach. Rating scale on Quality of life includes mobility, self care, activities at school, pain or discomfort, anxiety or depression, quality of sleep, involvement in outdoor play and activities at home.

DATA COLLECTION PROCEDURE

Study was conduct for the period of one month. Formal permission was sought and obtained from the medical officer of selected hospital in Salem and Parents of Haemophilic children who were participated in the study. Quality of life was assessed and rated as poor, average and good. Association found between demographic variables and Quality of life.

RESULTS AND ANALYSIS

Table 1: Frequency and Percentage distribution of Haemophilic children according to their demographic variables.

n=30

S.No	Demographic variables	Frequency	Percentage(%)
1	Age		
	1-5 years	4	13
	6-12 years	9	30
	12-18 years	17	57
2	Sex		
	Male	30	100
	Female	-	-

3	Residence Urban Rural	 1 29	 3 97
4	Class Studying I – V VI – VIII IX - X XI – XII No Schooling	 6 4 5 12 3	 20 13 17 40 10
5	Religion Hindu Muslim Christian Others	 29 - - 1	 97 - - 3

Table 2 Frequency and percentage distribution among haemophilic children according to their clinical variables. n=30

SI NO	Clinical characteristics of child	Frequency (f)	Percentage (%)
1.	HAEMOPHILIA TYPE Haemophilia A Haemophilia B	 26 4	 86.6% 13.3%
2.	TIME SINCE DIAGNOSIS At birth ≤ 5 years ≤10 years 11-19 years	 7 20 1 2	 23.3% 66.6% 3.3% 6.6%
3.	TYPE OF BLEEDING EVENTS Hemarthrosis Hematoma Uncontrolled bleeding from injury site Combined of one or two	 13 5 5 7	 43.3% 16.6% 16.6% 23.3%
4.	INVOLVEMENT OF JOINT No involvement Knee Hip Elbow Shoulder Ankle Wrist Multiple involvement	 7 2 2 1 - - - 18	 23.3% 6.6% 6.6% 3.3% - - - 60%
5.	HEAVY BLEEDING EPISODES IN LAST YEAR 1-3 times ≥4 times No episodes of bleeding	 6 1 23	 20% 3.3% 76.6%
6.	EPISODES OF HOSPITALIZATION > 6 months < 6 months	 30 -	 100% -
7.	EPISODES OF VISITING EMERGENCY DEPARTMENT > 6 months < 6 months	 1 29	 3.3% 96.6%
8.	FAMILY HISTORY OF HAEMOPHILIA Yes No	 11 19	 36.6% 63.3%
9.	CURRENT HAEMOPHILIA TREATMENT Factor VIII	 26	 86.6%

	Factor IX	4	13.3%
10.	TREATMENT APPROACH Symptomatic Primary prophylaxis	 - 30	 - 100%

With regard to the type of haemophilia, the majority of children 26(86.6%) were diagnosed with Haemophilia A, while only 4(13.3%) had Haemophilia B. Considering the time since diagnosis, most of the children 20(66.6%) were diagnosed within ≤5 years, followed by 7 (23.3%) diagnosed at birth. A very small proportion were diagnosed at ≤10 years1 (3.3%) and 2 (6.6%) at 11-18 years of age. In terms of bleeding events, hemarthrosis was the most frequently reported type 13 (43.3%). Other bleeding events included hematoma 5(16.6%) and uncontrolled bleeding from injury sites 5 (16.6%), while 7(23.3%) of children experienced a combination of bleeding events. With regard to involvement of joint, multiple joint involvement being the most common 18(60%). Among single joints, knee and hip involvement were each reported in7(6.6%) of cases, followed by elbow involvement 1 (3.3%). No cases of shoulder, ankle, or wrist involvement were reported, and7(23.3%) of children had no joint involvement. Regarding heavy bleeding episodes in the last year, the majority 23(76.6%) reported no episodes, while 6(20%) experienced 1–3 episodes and only 1(3.3%) reported ≥4 episodes. All children 30 (100%) had experienced hospitalization episodes lasting more than 6 months, while none had hospitalizations lasting less than 6 months. Most of the children 29(96.6%) had visited emergency department <6 months and 1(3.3%) had visited >6 months. Family history of haemophilia was present in 11(36.6%) of children, whereas19(63.3%) had no known family history. With respect to current treatment, the majority of children 26(86.6%) were receiving Factor VIII therapy, while 4(13.3%) were treated with Factor IX. All children 30(100%) were managed with primary prophylaxis, and none received symptomatic treatment.

Table 3 Rating scale for assessing quality of life among haemophilic children. n=30

S.no	Quality of life	Score	Frequency (f)	Percentage (%)
1.	Good	17-24	22	73.3%
2.	Average	9-16	8	26.6%
3.	Poor	1-8	-	0.1%

The above table shown that 22 (73.3%) children had good quality of life, 8 (26.6%) children had average quality of life and there were no children with poor quality of life with haemophilia.

Table 4 Association of quality of life among Hemophilic children with their selected demographic variables. n=30

S.No	Demographic Variables	df	$\chi 2$	Table value
1	Age	2	0.593	5.99
2	Sex	1	0.098	3.84
3	Residence	1	0.068	3.84
4	Class Studying	4	0.256	9.49
5	Religion	3	0.349	7.82

Table 5 Association of quality of life among haemophilic children with their selected Clinical variables. n=30

S.no	Clinical Variables	df	$\chi 2$	Table value
1	Hemophilia Type	1	0.016	3.84
2	Age of diagnosis	3	0.466	7.82
3	Type of Bleeding events	3	0.568	7.82
4	Involvement of joint	7	0.608	14.07
5	Number of bleeding episodes in last year	2	0.207	5.99
6	Episodes of hospitalization	1	0.029	3.84

7	No of visits to emergency department in the last year	1	0.732	3.84
8	Family history of hemophilia	1	0.209	3.84
9	Type of the clotting factor received	1	0.2423	3.84
10	Treatment approach	1	0.009	3.84

The above tables 4 and 5 repersented that there was no association between Quality of Life with demographic and Clinical Variables.

NURSING IMPLICATIONS FOR CHILDREN / ADOLESCENTS WITH HEMOPHILIA

- Promote treatment adherence by proper planning and identifying compliance barriers.
- Manage bleeding episodes in adolescence especially, hemarthrosis is the top clinical priority to avoid permanent joint damage and crippling arthropathy.
- Elevate and immobilize temporarily the bleeding limb
- Nurses must collaborate with adolescents to support healthy, active lifestyles while mitigating severe trauma risks to promote safe physical activity.
- Medication & Procedure Safety Precautions are advised to adolescents like avoid aspirin and non steroidal anti-inflammatory drugs (NSAIDs) like ibuprofen, coordinate factor replacement therapy in advance of any invasive diagnostic, surgical, or dental procedures.
- Supporting the psycho social needs of an adolescent by normalizing the condition and by guiding them to connect with the Haemophilia Community.

CONCLUSION

Research highlights that Health-Related Quality of Life (HRQoL) in children with hemophilia is heavily influenced by disease severity, joint health, and the use of prophylactic factor therapy. Key studies use specialized tools like the Haemo-QoL and PedsQL questionnaires to evaluate physical, emotional, and social well-being. Younger children (4–12 years) show the highest impairment in the family domain, while older adolescents (13–16 years) experience the greatest challenges in sports, school, and social integration. Studies show that better access to and adherence to prophylactic therapy significantly improves quality of life by reducing spontaneous bleeds and preserving joint mobility.

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