

# Quality of life in hemophilic children on prophylactic or on-demand treatment regimens in Iran



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## OBJECTIVES

Treating a chronic disease such as hemophilia is to improve the symptoms and quality of life (QOL) of the patients. This study aimed to assess the QOL of hemophilic children between 4-16 years old and compare it between patients receiving prophylactic or on-demand treatments in Iran, as a developing country.

## RESULTS

➤ **The Mean QOL** in the first group receiving prophylactic and on-demand treatments were  $2.6 \pm 0.3$  and  $3.33 \pm 0.4$  respectively ( $P < 0.001$ ).

❑ All dimensions except "treatment" and "feeling" were different between groups 1-P & 1-D .

❑ Patients in the second group had poorer QOL than patients in first group receiving on-demand treatment [1-D] ( $P < 0.001$ ).

❑ In first age group, the highest impairment in patients, regardless of their treatment regimen, were family and physical dimension respectively.

❑ In the second age group, the highest impairment was in the sport's dimension.

➤ **Mean age of the children** was 5.6 and 11.9 in groups 1 and 2 respectively. **Age of parents** was in the range of 31 to 35 in the first group and 35 to 54 in the second group. Most of the families had one or two children

➤ In both groups, more than 85% of the children suffered from Hemophilia A and about 15% suffered from hemophilia B.

➤ In group 1 ,Inhibitor antibody titer was positive jsut in two evaluated children in group 1-D. it was not determined in all of the group 2 patients.

➤ **Mean frequency of bleeding** was 2.45 in former (1.4 in group 1-P and 3.8 in group 1-D) and 3.3 in latter groups. The difference was statistically significant ( $P = 0.001$ ). About, 36% in group 1 and 53.3% in second group experienced four or more episodes of bleeding in a month.

➤ **Injection times:** Most of the children on prophylactic treatment (66.7%) injected factor once a week followed by two (20%) and three (13.3%) injections a week. Average times of injection per month was 5.7 in patients receiving prophylactic treatment method. There was no documented data in this regard in patients who received the on demand treatment.

➤ Overall in both groups , **nurses performed 70% of injections and remaining 30% was performed by parents .**

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## METHODS

In this descriptive-comparative study, we enrolled 90 patients from two main hemophilia care centres in Tehran, 60 patients in the **age group 4-7 (group 1)** and 30 in the **age group 8-16 (group 2)**. Half of the patients in first group were receiving prophylactic (**group1-P**) and half were receiving on-demand treatment (**group1-D**) . Patients in second group only received on-demand treatment.\*

The research tool used was the short form of the **Hemo-qol** questionnaire, which assesses QOL in 9 dimensions (physical, feeling, family, friends, others, school, attitude, treatment, and behaviour). In this instrument, higher points correspond to lower QOL. Chronbach alpha of original questionnaire for all dimensions was 0.84. After translation into persian, content validity approved by an expert group which was consist of a Hematologist,a nurses and an epidemiologist .The internal reliability of questionnaire in all dimensions which was determined by chronbach alpha was (0.74). Test-retest correlation was evaluated on 15 children within 10 days and was 0.72.

All analyses used a two-sided test of significance and the level of 0.05 was considered positive. Paired and independent T test, Mann Whitney, Fisher, and Chi Square tests were applied as appropriate

\*we had just 30 young(4-7 Y old) cases on propophylaxis , then randomly selected just 30 cases from the same age group who received OD treatment and the same number of cases in another age group.(Frequency matching)

## QOL scores in groups

8-16 years old (Group 2)		4-7 years old (Group 1)			Group
P value	On-Demand	P value	On-Demand(1-D)	Prophylaxis (1-P)	QOL Dimensions
<0.001	12.9±2.4	<0.001	3.6±0.6	2.47±0.9	physical
<0.001	14.1±5	0.06	2.29±0.9	2.2 ±1	Feeling
<0.001	13.1±1.9	0.003	2.7±1.1	1.9±1.1	Attitude
<0.001	14.8±2.4	0.015	3.4±0.6	3.8±0.7	Family
<0.001	11.8±3.9	0.018	3.08±1	2.52±0.7	Friends
<0.001	11.03±3.2	<0.001	2.8±0.9	2.03±0.9	Others
<0.001	16.7±2.3	0.018	3.05±0.8	2.29±0.9	Sport
	11.6±2.1	-	-	-	Behavior
<0.001	11.8±8.3	0.06	2.8±1.2	2.22±1.2	Treatment
<0.001	13.9±3.5	<0.001	3.33±0.4	2.6±0.3	ALL

## CONCLUSIONS

➤ compared with prophylactic therapeutic method, in hemophilic children who receive on demand treatment the quality of life is poorer.

➤ The decrease in the quality of life will be intensified by age in on demand treatment group.

➤ Increased frequency of bleeding in lower ages has more effect on quality of life than in older ages.

➤ injection times per week and injector person seem to have not influence on QOL in patients.

