

Evaluation of quality of life in children with hemophilia

Gonul Aydogan, Merve Kilic, Zafer Salcioglu, Ferhan Akici, Hulya Sen, Cengiz Bayram, Gonca Keskindemirci, Nuray Aktay Ayaz, Ebru Yilmaz, Nihal Ozdemir

Istanbul Kanuni Sultan Suleyman Education and Research Hospital



Aim

In this study, the quality of life index was used to evaluate the standards of quality of life among mild, moderate and severe hemophilia patients that are under prophylaxis or not, with or without inhibitors and with or without target joints. The same index had been applied to their parents too.

Materials and methods

The study group included 40 hemophilia patients between 8-12 years of age that were followed up in Istanbul Kanuni Sultan Suleyman Education and Reserach Hospital between April 2014-September 2014 and their parents. Patients were grouped as mild, moderate and severe according to their factor levels. Twenty-six of the patients were having prophylaxis, while 24 were not having any prophylaxis. Datas of the patients were collected by socio-demographic data sheet and PedsQL hematology/oncology module. At the sociodemographic data sheet there was 27 questions. Questions were related to pain, tenderness, nausea, interventional anxiety, treatment anxiety, cognitive problems, physical appearance cognition and communication.

Results

Among 40 patients 23 were grouped as severe, 11 as moderate, 6 as mild. Prophylaxis were being applied to 16. In 3 patients there was inhibitors. In 13 patients there was target joints and 27 had no target joints. Patients having prophylaxis complained less about pain and tenderness, but they have more communication problems. Patients without any target joint have less pain and tenderness. Patients in the severe hemophilia group complained more about pain and tenderness. The most important factors that were pointing out to quality of life were frequent visits to the hospital, recurrent treatment needs, joint damages and pain. Joint damage was found to be the most common reason of pain and tenderness.

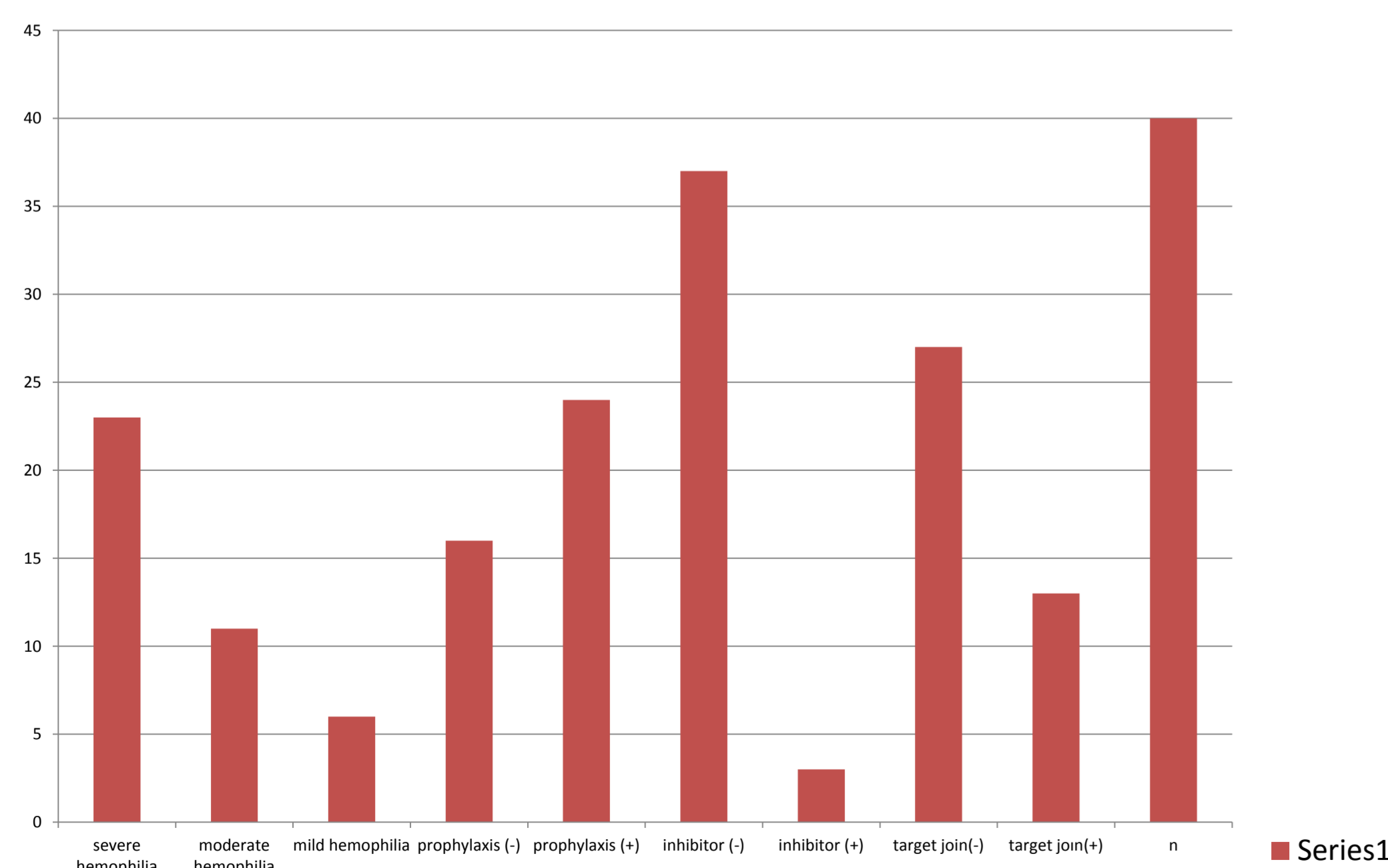
When the parents of mild, moderate and sever hemophiliacs were evaluated, no difference was found regarding to health related quality of life between groups. Parents of children under prophylaxis were having more significant communication problems than those who were having no prohylaxis. Parents of children with target joints had significantly elevated pain, procedural anxiety and treatment anxiety when compared to parents of children without any target joints.

	Target joint (-) n:27	Target joint (+) n:13	P
Pain	52,88±16,26	66,67±18,01	0,025
Bulantı Nausea	87,59±10,32	85,77±16,18	0,667
Interventional anxiety	73,77±22,01	83,33±24,06	0,219
Treatment anxiety	90,12±16,02	91,67±14,83	0,772
Tenderness	78,09±17,62	72,44±16,1	0,335
Cognitive problems	66,3±26	67,69±14,23	0,858
Physical appearance cognition	55,04±22,57	75±14,43	0,019
Communication	75±23,8	76,92±23,61	0,812

The standarts of quality of life in target joint (-) and (+) groups

	Mild n:6	Moderate n:11	Severe n:23	P
Pain	54,89±17,16	63,64±10,39	87,5±11,18	0,0001
Nausea	86,67±5,16	82,73±16,79	89,13±11,04	0,376
Interventional anxiety	70,83±24,58	74,24±28,98	79,71±19,6	0,643
Treatment anxiety	88,89±17,21	87,12±16,82	92,75±14,72	0,596
Tenderness	81,94±13,35	62,88±12,56	81,16±16,9	0,007
Cognitive problems	80±18,17	50,91±18,68	70,87±22,04	0,013
Physical appearance cognition	63,89±22,15	54,55±17,23	72,46±20,63	0,06
Communication	52,78±19,48	62,12±24,82	88,04±14,61	0,0001

The standarts of quality of life in mild, moderate and severe hemophila groups



Distribution of patients with hemophilia in the study group

	Prophylaxis (-) n:16	Prophylaxis (+) n:24	P
Pain	69,53±18,8	57,29±16,86	0,038
Bulantı Nausea	82,81±12,64	89,79±11,56	0,079
Interventional anxiety	70,31±25,81	81,25±20	0,140
Treatment anxiety	86,46±19,21	93,4±12,03	0,167
Tenderness	71,35±19,95	79,51±14,53	0,142
Cognitive problems	64,38±25,16	68,33±21,25	0,595
Physical appearance cognition	60,94±22,09	69,79±19,94	0,195
Communication	61,98±23,17	84,72±19,14	0,002

The standarts of quality of life in prophylaxis (-) and (+) groups

	Pain	Tenderness	Cognitive problems	Communication
Mild / Moderate	0,257	0,049	0,023	0,587
Mild / Severe	0,0001	0,993	0,604	0,001
Moderate / Severe	0,009	0,007	0,032	0,001

Tukey Multiple comparison test

Conclusions

By early commencing of prophylactic treatment , home treatment and by long acting factor preperates the applications to the hospital, time spent in the hospital, treatment needs and complications of disease may be lessened. By the way these precautions will increase the patients quality of life.



Poster Presented at:

DOI: 10.3232/psa.eu.VFH2016.2016

Quality of Life
Gonul Aydogan

197--PO-M
910ZHM