

Employee of: Employee of CSL Limited, J. Powell
 Employee of: Employee of CSL Limited, K. St Ledger
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 Employee of: Employee of CSL Limited, M. Hofmann
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Adhering to Prophylaxis and Anxiety; is There a Relationship Needed to be Noticed? Ege Adult Haemophilia Center Experience

F. D. KOSEOGLU^{1,*}, F. SAHIN¹,
 Z. MEHREKULA¹, G. SAYDAM¹, O. ONEN
 SERTOZ²

¹Hematology, Ege University; ²Psychiatry, Ege University, Izmir, Turkey

Introduction: Haemophilia is a congenital, lifelong disorder and characterized by spontaneous and post-traumatic bleeding events. The treatment for severe haemophilia is prophylaxis with clotting factor. Regular prophylaxis protects against spontaneous bleeding which leads to joint damage that may result in long-term disability. The objective of this study was to find the relationship between adhering to prophylaxis and having anxiety in adults with haemophilia treated at the Ege Adult Hemophilia Center.

Methods: Sociodemographic features were obtained from a short questionnaire which given to patients with State-Trait Anxiety Scale. A cut point of 40 was used to detect clinically significant symptoms for the anxiety scale. Adherence to prophylaxis was calculated by dividing the total number of IU prescribed by the total estimated number of IU and multiplying by 100 (Adherence (%) = total prescribed IU/total estimated IU × 100). Objective adherence was divided into two groups of adherence ≥75% and adherence <75%.

Results: Ninety patients, 30.6% ($n = 90/294$) of the adult population with haemophilia were enrolled to the study. Eighty five percent of individuals were Hemophilia A and 15% were B. The median age of the patients was 39 years. Eighty eight percent of the patients were in prophylactic use of hemophilic factor, 12% percent of the patients use hemophilic factor on demand. Adherent patients were found 66% and non adherent patients were 34%. The findings revealed no significant correlation between state and trait anxiety scores along with age, adherence to prophylaxis, age at diagnosis, severity of hemophilia, family history of haemophilia, distance to haemophilia center, number of bleeding per year, education and employment status.

Discussion/Conclusion: Experiencing anxiety in occasional times and situations is a normal part of routine life. However, people with chronic and/or life threatening disorders are tend to be more anxious. The face to face visits reflects that patients with

haemophilia have anhedonia and anxiety. But anxiety scores were not high as we predicted although we could not find an association between anxiety and adherence to prophylaxis. We defend that self reports of the patients are not reflects the real situation and patients with haemophilia and their families should be provided with psychological and social support.

Disclosure of Interest: None declared

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Radiosynoviorthesis in the Treatment of Recurrent Hemarthrosis in Patients with Haemophilia: Experience in a Single Center

F. QUEROL-FUENTES^{1,2,*}, M. QUEROL-GINER¹,
 S. PÉREZ-ALENDA^{1,2}, A. IRADI³, J.
 J. CARRASCO^{1,4}, C. CRUZ-MONTECINOS^{5,6},
 S. BONANAD²

¹Department of Physiotherapy, University of Valencia; ²Haemostasis and Thrombosis Unit, University and Polytechnic Hospital La Fe; ³Department of Physiology, Faculty of Medicine and Odontology, University of Valencia; ⁴Intelligent Data Analysis Laboratory, University of Valencia, Valencia, Spain; ⁵Department of Physical Therapist, University of Chile; ⁶Laboratory of Biomechanics and Kinesiology, San José Hospital, Santiago, Chile

Introduction: In patient with haemophilia, bleeding disorders mainly affect synovial joints causing synovitis and cartilage alteration, increasing the risk of rebleeding and resulting in haemophilic arthropathy. One of the first choice treatment in the synovitis is the radiosynoviorthesis. The main benefits of this treatment are: reduction of synovial inflammation (within a period of 2 to 6 months), decreased pain and bleeding frequency reduction. The objective of this study is to evaluate the effectiveness of radiosynoviorthesis in the reduction of the bleeding frequency in patients with haemophilia.

Methods: In this retrospective study, data of synoviorthesis procedures performed in the period from 2004 to 2015 were collected. These procedures were conducted in the Haemostasis and Thrombosis Unit, Hospital La Fe, Spain. In this center, radiosynoviorthesis are performed in chronic synovitis, confirmed by clinical or ultrasonographic criteria and/or evidence of haemarthrosis (2–3 haemarthrosis/joint/year). This procedure was carried out with the infiltration of the radionuclide Renio-186 (elbow/ankle/shoulder) and Itrio-90 (knee). According to normal data distribution, t-test or Wilcoxon test was performed to evaluate the existence of significant differences in the number of bleedings.

Results: A total of 174 synoviorthesis (83 knees, 58 elbows, 32 ankles and 1 shoulder) were performed during the study period in 71 patients (53 severe, 9

moderate and 9 mild; age: 31.68 ± 13.22 [4.34–73.38] years old). The average number of procedures per patient was 2.45 ± 1.87 [1–9]. The total number of bleeding episodes during the 12 months pre-synoviorthesis was 586 (201 in knees, 267 in elbows, 115 in ankles and 3 in shoulder) with a joint bleeds average of 3.37 ± 3.07 (2.42 ± 2.55 in knees, 4.6 ± 3.54 in elbows, 3.59 ± 2.7 in ankles and 1.5 ± 1.12 in shoulder). In the 12 months post-synoviorthesis the number of bleedings was 168 (56 in knees, 91 in elbows, 21 in ankles and 0 in shoulder) with an average of 0.97 ± 1.60 (0.67 ± 1.0 in knees, 1.57 ± 2.3 in elbows, 0.66 ± 0.97 in ankles and 0.0 ± 0.0 in shoulder). In all cases, a statistically significant decrease ($P < 0.001$) in the haemorrhagic frequency was obtained.

Discussion/Conclusion: In haemophilic patients with synovitis, radiosynoviorthesis with Renio-186 and Itrio-90 is an effective procedure to decrease the frequency of intra-articular bleedings.

Disclosure of Interest: None declared.

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Physical Activity In Haemophilia: Hemorrhagic Risk And Factor Levels (myPKFiT)

F. QUEROL-FUENTES^{1,2,*}, S. PÉREZ-ALENDA^{1,2}, J. J. CARRASCO¹, J. EDUARDO MEGÍAS³, J. L. POVEDA³, S. HAYA², A. R. CID², S. BONANAD²

¹Department of Physiotherapy, University of Valencia;

²Haemostasis and Thrombosis Unit, University and Polytechnic Hospital La Fe; ³Pharmacy Department, Drug Clinical Area, University and Polytechnic Hospital La Fe, Valencia, Spain

Introduction: The increase in life expectancies in haemophilic patients reinforces the need to promote a physically active lifestyle. According to expert recommendations and the World Health Organization (WHO), adults should perform 10,000 steps a day and accumulate at least 150 minutes a week of moderate-intensity physical activity. To reduce the risk of bleeding in these patients it is necessary to adjust the amount and intensity of physical activity

with prophylaxis and trough levels. The objective of this study is to determine the amount of physical activity and joint bleeds in patients with haemophilia in prophylactic treatment controlled by myPKFiT.

Methods: 7 patients with severe haemophilia type A (Age: 37.00 ± 8.23 [28.00–49.00] years old; Weight: 84.77 ± 29.36 [67.20–150.20] kg; Height 1.75 ± 0.11 [1.54–1.85] m; IMC: 27.56 ± 8.28 [20.69–44.85] kg m^{-2}) from the Haemostasis and Thrombosis Unit of the Hospital La Fe, Valencia, Spain were included. The Fitbit Charge HR activity wristband was used to quantify the amount and intensity of daily physical activity performed during 10 months. To adjust the prophylaxis treatment, a standalone web-based software that uses a published population pharmacokinetic (PK) model together with a Bayesian algorithm (myPKFiT, Baxalta) was used. myPKFiT was developed to predict PK parameters in patients with hemophilia A with only two blood samples.

Results: Table 1 depicts the results obtained. In the 10 months follow-up, only 2 ankle hemarthrosis were recorded (1 spontaneous and 1 provoked). The trough levels were ≥ 3 IU in all patients.

Discussion/Conclusion: Despite arthropathy, haemophilic patients with trough levels ≥ 3 IU are physically active and are able to comply with the recommendations of experts and WHO with a low risk of bleeding. However, further studies are needed to include a larger sample size.

Disclosure of Interest: None declared.

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Dutch Hemophilia Patient Registry and Digital Infusion Log

G. GOEDHART-DE WOLF^{1,*}, K. FISCHER², M. DRIESSENS³, F. VAN DER MEER¹

¹Thrombosis and Hemostasis, Leiden University Medical Center, Leiden; ²Van Creveldkliniek, University Medical Center Utrecht, Utrecht; ³Netherlands Hemophilia Patient Society, Nijkerk, The Netherlands

Introduction: For rare diseases like hemophilia, with good though very expensive treatment available, a

Table 1 Arthropathy, joint bleeds, pharmacokinetic parameters and activity data

Patient	Gilbert score	Joint Bleeds	rFVIII		Trough level	Steps /day (mean \pm sd)	Fairly / Very active (mean \pm sd)
			consumption / day (IU)	half-life (hours)			
1	36	1	822.9	15.8	≥ 3	11599.3 ± 3765.8	99.4 ± 78.7
2	19	0	644.6	14.6	≥ 3	13991.1 ± 2937.6	291.0 ± 107.7
3	23	0	501.4	16.5	≥ 3	9610.5 ± 3601.3	81.6 ± 53.6
4	17	0	714.3	22.4	≥ 3	10300.2 ± 3785.6	72.7 ± 51.2
5	23	1	483.0	18.5	≥ 3	15657.5 ± 5198.8	69.0 ± 78.2
6	14	0	1159.0	12.3	≥ 3	6980.7 ± 3891.3	64.7 ± 60.0
7	5	0	476.5	12.8	≥ 3	10671.6 ± 2996.5	45.1 ± 23.9