Adherence to prophylactic treatment in patients with haemophilia in Germany

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Introduction

In severe haemophilia, the benefits of prophylactic treatment of haemophilia include decreased frequency of bleeding episodes and the prevention of haemarthropathy. We investigated the VERITAS-Pro questionnaire in German patients to study adherence and potential impact factors in patients of all ages. Supplementary information was assessed regarding the severity of haemophilia, treatment regimen, self or non-self factor application, care in a haemophilia centre, pain levels, and co-morbidities.

Methods

In 2014 all members of the German haemophilia patient organisation (DHG) who suffer from moderate (1-5%) or severe (<1%) haemophilia and are on continuous prophylactic treatment were asked to complete the VERITAS-Pro questionnaire. The patients reviewed a German translation of the validated VERITAS-Pro questionaire that contains six different subscales (time, dose, plan, remember, skip and communicate) to determine adherence to treatment. Each subscale concerns a specific issue of haemophilia care represented by four questions each: Necessity and dosing of clotting factor concentrates (subscales: "Time", "Dose") in relation to prior doses (subscales: "Remember", "Skip") and if the physician was contacted (subscale: "Communicate"). Also management of clotting factor stock was asked (subscale "Plan"). Each item is quantified on a five-point scale ranging from "Always" to "Never". Scores can range from 24 to 120 with higher scores indicating poorer adherence. Additionally, data about their social status, pain levels and co-morbidities were evaluated. Following statistic tests were carried out: Mann-Whitney-U-Test, M-U-Test und Kruskal-Wallis-Test.

Patients characteristics (n = 397)	% (n)
Age of patients (years)	
0 - 14	25.4 (101)
15 - 19	7.6 (30)
20 - 59	47.6 (189)
within: 20-29	13.1 (52)
30-39	8.3 (33)
>60	11.1 (44)
No data	8.3 (33)
Type of haemophilia	
haemophilia A	86.4 (343)
haemophilia B	13.6 (54)
haemophilia, severe	92.7 (368)
haemophilia, moderate	7.1 (28)
no data	0.3 (1)
Treatment modalities*	
patients treated in haemophilia centres	86.6 (344)
prophylactic treatment	100 (397)
Pain level	
mobil without pain	44.6 (177)
mild pain	34.8 (138)
moderate pain	1.3 (5)
severe Pain	12.8 (51)
no data	6.5 (26)
Need of help	
no	67.8 (269)
rarely	11.8 (47)
occasionally	12.1 (48)
frequently	8.1 (32)
always	0.3 (1)
Factor substitution	
self	66.0 (262)
family/physician/others	23.4 (93)
self/family etc.	8.3 (33)
no data	2.3 (9)
Comorbidities	
hepatitis C	39.3 (156)
HIV	23.4 (93)
other	18.1 (72)

Total VERITAS-Pro score - description and comparison of different patient age groups

Age (years)	n	Mean	SD	Median	Min-Max	15-19	20-59	≥ 60	adherence** n (%)
0-14	85	30.0	5.4	29.0	24 - 49	0.001	0.000	0.059	85 (100%)
15-19	26	35.7	8.5	33.5	24 - 55	-	0.019	0.298	26 (100%)
20-59	159	41.1	11.7	38.0	24 - 86	-	-	0.001	140 (88.1%)
20-29	44	38.2	10.7	35.0	24 - 68				85 (193.2%)
30-39	27	45.6	13.7	43.0	24 - 86	0.009#			26 (96.3%)
>=60	33	34.3	10.5	32.0	24 - 66	-	-	-	31 (93.9%)
total	303	36.7	11.0	34.0	24 - 86	-	-	-	282 (93.1%)

(header spanning: VERITAS-Pro score; versus ...*; adherence**)

* pairwise comparison of age groups, p-value according to Mann-Whitney-U-test
**Number and percentage of patients with VERITAS-Pro score < 57
\# 20-29 vs. 30-39, p-value according to Mann-Whitney-U-test

VERITAS-Pro score - Subscale scores in correlation to age groups age
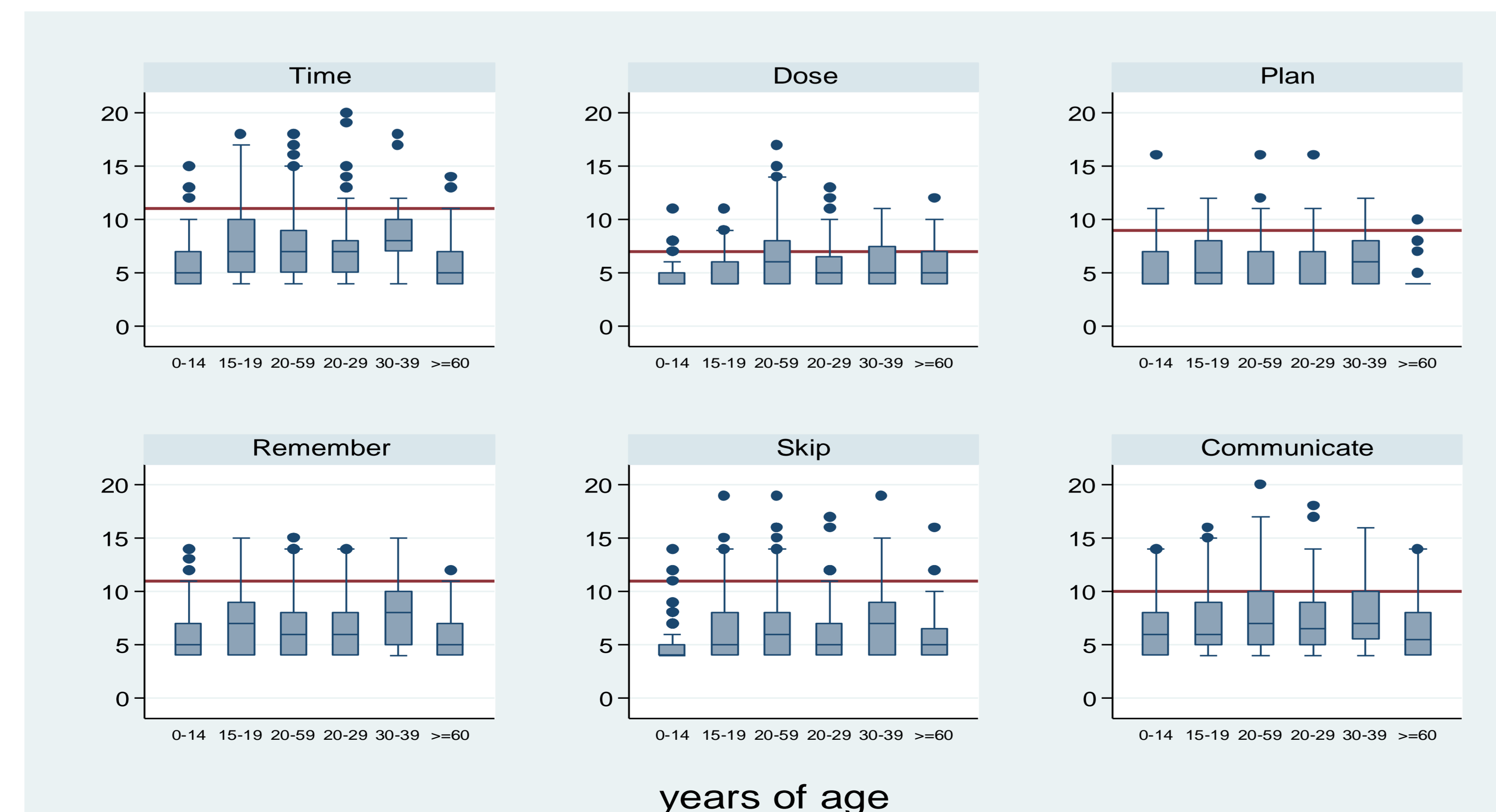
years of age

Definition of outlier:
value which lies more than 1.5 times the length of box from the upper or lower end of the box

Total VERITAS-Pro score - potential impact factors and age groups

Definition of outlier:
value which lies more than 1.5 times the length of box from the upper or lower end of the box
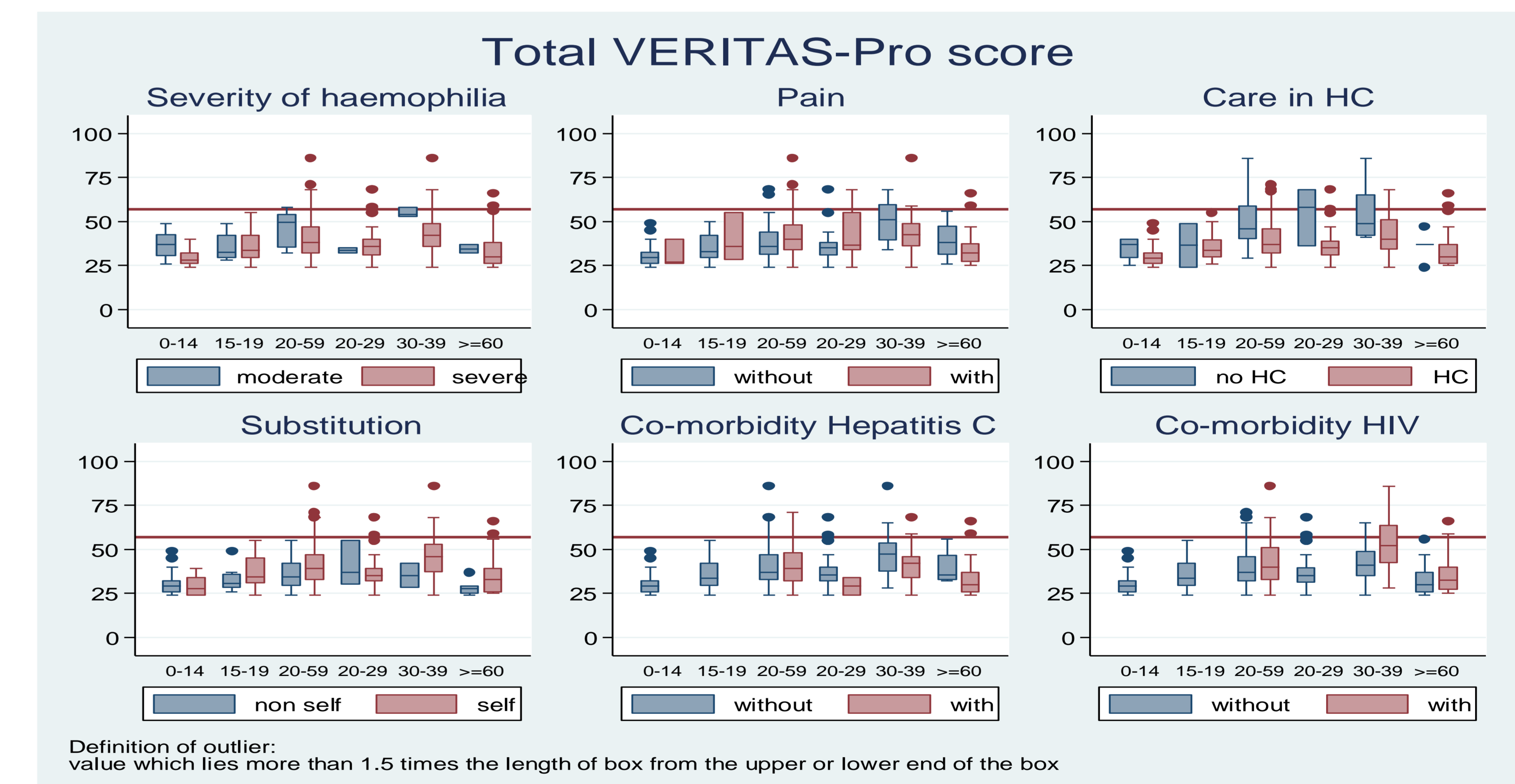
Summary

This study provides evidence that adherence differs between different age groups of patients and is highest in patients between 0 and 14 years of age followed by the age group 15-19 years, and then ≥60 years. The percentage of adherence in this study cohort was 100% for patients 0-19 years old, 88.1% for patients 20-59 years old, and 93.9 % for patients over 60.

Within the patients aged 20+ care by a haemophilia centre was the only significant indicator for better adherence. The tendency of better adherence of patients aged > 60 compared to patients 20-59 may be explained by the significant association of the occurrence of pain with increasing age although a significant influence of pain on the adherence levels could not be demonstrated.

The findings derived from the VERITAS-Pro questionnaire and the identification of additional impact factors could facilitate the design of tailored interventions to promote adherence. Future studies should be conducted to confirm the link between adherence, patient characteristics and treatment outcomes.

References:

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