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 received a German translation of the validated VERITAS-Pro questionnaire 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 (subscale: “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 statistical tests were carried out: Mann-Whitney-U-Test, M-U-Test and Kruskal-Wallis-Test.

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 20-69 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 95.9% for patients over 60.

Within the patients aged 20-69 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 an 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:


Miesbach W, Kalnins W. Adherence to prophylactic treatment in patients with haemophilia in Germany. Haemophilia in press.

[Tables and diagrams related to the patients characteristics, total VERITAS-Pro score, subscale scores in correlation to age groups, and summary of the findings.]