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Perspective on quality of life in hemophilia patients from Romania using EQ-5D-5L questionaire

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Abstract

Hemophilia is a rare X-linkated bleeding disorder which causes spontaneous or secondary bleeding. This disorder used to be treated with plasma or cryoprecipitate, but since clotting factor precipitates became available these have become standard of treatment. Unfortunately, in Romania, this treatment has been approved very late, and first only for on-demand treatment. Even though now it is approved for both on-demand and prophylactic treatment, the funding is insufficient for all hemophilia A patients, therefore access to treatment is difficult in some areas of the country and most patients have started prophylactic treatment very late, after articular complications already occured. Our study tried to asses the quality of life, in hemophilia a patients, comparing the on-demand population with the prophylactic population. It has shown a lower quality of life in patients with prophylactic treatment, which leads us to believe that the late start of prophylactic treatment and the severity of the cases selected for prophylactic treatment leads to the lower quality of life. This reinforces the need for a more appropriate funding from the government for the prophylactic treatment of Hemophilia patients, at younger ages, as this would lead to patients being able to become active members of society, with a better quality of life and lower costs for health systems.

Keywords: Quality of life; EQ-5D-5L; Hemophilia.

Introduction

Hemophilia is a rare X-linkated bleeding disorder which manifests in spontaneous or post-traumatic bleeding. At first, it was treated with plasma or cryoprecipitate products, but since then clotting factor precipitates have been introduced, which reduced secondary viral infections, improved quality of life and bleeding control. In Romania, this treatment has been approved very late, and to this date most of the patients have access only to on-demand treatment. The profilaxis treatment is accessible only in some regions of the country, due to a shortage of hematology specialists and centers.

Measuring quality of life is not used on a regular basis in Romania in clinical practice, and is a area of low interest for most clinicians. Nevertheless, it is an important factor to consider when treating hemophilia patients and a great tool that can be used to personalize treatment.

In our country there are about 800 diagnosed hemophilia patients, most of which are male patients. Even though the lot examined in this paper is a rather small one, it can give us an idea of quality of life in hemophilia patients in Romania in 2022.

Materials and methods

We have selected a lot of 45 adult male patients, with ages between 23-70 years, diagnosed with Hemophilia A. The lot was divided into two groups: Prophylactic treatment group that consisted of 21 patients, and the on-demand group, that consisted of 24 patients. All patients completed the EQ-5D-5L self-complete questionnaire. Moreover, data such as age, treatment and paraclinical determinations were collected from patient charts. The data was centralized and analysed using SPSS tools.

Results

The two groups of patients were compared in regards to median age, education, profession, marital status, gravity of the disease and there were no significant statistical differences found.

There were no significant statistical differences when it comes to number of hemoragic events/per year between the 2 groups, but there was a median of higher number of hemoragic events in the group with prophylactic treatment, as seen in Table 1 which indicated that number of hemoragic events is a decision factor to starting a prophylactic treatment.

Table 1: Hemoragic events comparison.

Kruskal-Wallis H (equivalent to Chi square) =	0.8285
Degrees of freedom =	1
P value =	0.3627

Table 2: Kruskal-Wallis for activity comparison.

Kruskal-Wallis H (equivalent to Chi square) =	2.5658
Degrees of freedom =	1
P value =	0.1092

Table 3: Kruskal-Wallis for pain comparison.

Kruskal-Wallis H (equivalent to Chi square) =	2.6091
`Degrees of freedom =	1
P value =	0.1063

Table 4: Anxiety comparison.

Kruskal-Wallis H (equivalent to Chi square) =	1.6319
Degrees of freedom =	1
P value =	0.2014

Table 5: Overall EQ-5D-5L score.

Kruskal-Wallis H (equivalent to Chi square) =	4.8752
Degrees of freedom =	1
P value =	0.0272

Table 6: Self-assesment score.

Kruskal-Wallis H (equivalent to Chi square) =	3.1193
Degrees of freedom =	1
P value =	0.0774

When it comes to selfcare, there were semnificative differences between the 2 groups, the p value being 0,10128. Those with prophylactic treatment, proved to have a better outcome in this area, which also is in accordance with general practice and also medical data worldwide.

Comparing the two groups based on activity, pain levels, there were no significant statistical differences, but there was a higher score in the prophylactic treatment group, as seen in Tables 2 and 3. When dealing with a larger lot of patients, there might be semnificative differences.

The anxiety levels have proven to be higher in the prophylactic group as well (Table 4) even though there were no significant differences when analysing this lot, differences might occur at a higher number.

The overall score for the EQ-5D-5L test was higher in the prophylactic group than in the on-demand group, but the self-assesment score was higher in the on-demand group than in the prophylactic group.

Discussion and conclusions

Most of our analysis was in accordance with our expectations and the medical data provided by our peers. The higher number of hemoragic events/year was higher in the prophylactic treatment group, but that was not as a result of the prophylactic treatment being given, but it was the motive for treatment being started.

This is in accordance with general practice in Romania, because the lack of sufficient funds, makes us prioritize patients, and the milder ones, those that have no or few hemoragic

events without prophylactic treatment will receive on demand treatment and those with higher numbers of hemoragic events will be given prophylactic treatment. It is our desire to start treatment earlier, when patients have fewer complications and a better quality of life, but when that is not possible, we choose to maintain an acceptable quality of life for all patients.

Patients with prophylactic treatment proved to have a better selfcare score, which is in accordance to clinical practice and studies worldwide. Even though the cases are most often more severe, the slefcare is better due to treatment improvements.

In regards to activity, anxiety and pain scores, there were no significant differences. This might be due to the size of the examined lot, or due to the fact that by choosing severe cases for prophylactic treatment, and those that are milder receive on-demand, we managed to obtain a quality of life equal in both groups. Physical activity and sports are still not attainable for hemophilic Romanian patients in either groups. This is due to complications of the dissease, comorbidities, anxiety and also lack of sufficient treatment. We hope that by rasing awareness, the government will understand the benefits of supplementing funding for prophylactic treatment.

The overall score for the EQ-5D-5L test was higher in the prophylactic group. This is due to the severity of cases selected and the late start of prophylactic treatment. It is another proof that we need to receive better funding for hemophilia programs, and is in accordance to the self-assesment scores, which were higher in the on-demand group, with almost significant differences.

This paper is part of a larger study which we are undergoing. We hope that by continuing our work.

Declarations

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