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The Impact of Social Status of Adult Hemophilia Patients from a Single German Treatment Centre on Outcome Parameters

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Background

Clinical outcomes in haemophilia are mainly determined by the severity of clotting factor deficiency, treatment regimen (prophylaxis vs. on-demand), availability of clotting factor concentrate, and age. Only few information on the impact of additional patient-related factors such as education, social status, or impact of the disease on the patient's life on treatment outcome is available [1,2].

Aim

To explore the influence of factors from the social history of patients with haemophilia and von Willebrand s Disease from a single centre and the impact of the disease on the patient's life on clinical outcomes.

Methods

Patients with bleeding disorders routinely visiting the Haemophilia Treatment Centre completed a questionnaire including socio-demographic data, questions regarding social status, and a generic quality of life (QoL) questionnaire (SF-36).

Social status was categorized into 3 groups (high, medium, and low) based on patients' school and professional education, their employment status and income as well as on their parents' school education.

Patients were asked about the ***impact of the bleeding disorder on different aspects of their lives*** (education, childhood, job, career, social contacts, and leisure). Two groups with high and low impact on their lives were categorized.

In addition, clinical data were collected from patient files.

Results

58 patients with bleeding disorders (38 severely affected) with a mean age of 38 16 years (range 18-80) were enrolled in the study. Details of patient characteristics are shown in Tables 1 and 2.

According to our definition 15 patients were categorized as having a high, 35 as having a medium, and 7 as having a low ***social status***.

More than half of the patients reported that ***the bleeding disorder had an impact*** on their school education (50.9%), childhood (58.2%), and leisure (60%). Half of the patients reported an impact of haemophilia on at least 2 different aspects of their lives.

Results

Patients with different ***social status*** showed no significant differences regarding clinical outcomes (number of bleeds, number of target joints, orthopaedic status and pain). A non-significant trend towards a stronger impact of the disease on patients' lives, and a trend towards a better QoL (Figure 1) and better life satisfaction was seen in patients with a higher social status.

Patients with a ***high impact of the bleeding disorder on their lives*** had a worse orthopaedic joint score ($p<0.009$) as shown in Figure 2, and reported more pain ($p<0.017$) than patients with a low impact on their lives. No differences were seen for the other clinical outcomes. By contrast patients with a high impact of the bleeding disorder on their lives were less satisfied with their lives ($p<0.002$) and reported a significantly worse QoL in all domains of the SF-36 (Figure 3).

Parameter	Patients with bleeding disorders (n=58)
Haemophilia A (HA) all	47
- HA severe	32
- HA moderate	4
- HA mild	11
Haemophilia B (HB) all	9
- HB severe	4
- HB moderate	4
- HB mild	1
Von Willebrand disease	2
- Type 3 severe	2

Table 1: Patient characteristics: Diagnoses

Parameter	Patients with bleeding disorders (n=58)
Treatment regimen	n (%)
- primary prophylaxis	6 (10.3%)
- secondary prophylaxis	17 (29.3%)
- on demand	35 (60.3%)
Annual bleeding rate	M SD
- all bleeds	6.9 9.0
- joint bleeds	5.0 7.3
Orthopaedic joint score	8.5 8.6
Target joints (median, range)	0.38 0.70 0 (0-3)
BMI (median, range)	24 2.9 24 (16-30)
Pain VAS (median, range)	4.11 2.7 4 (0-10)

Table 2: Clinical data

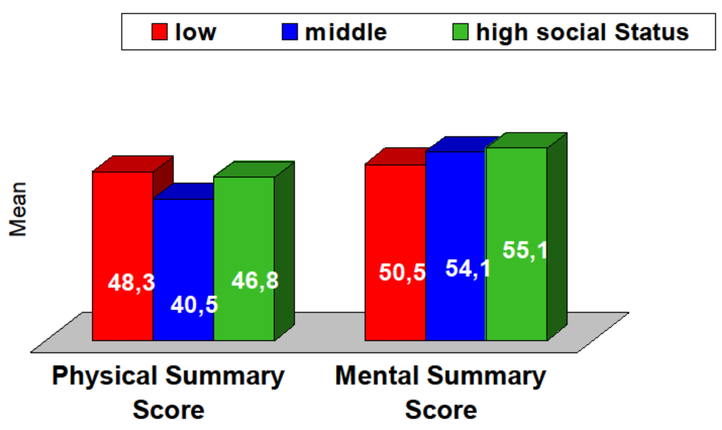

Figure 1: Quality of Life (SF-36) across patients with bleeding disorders from different social status groups

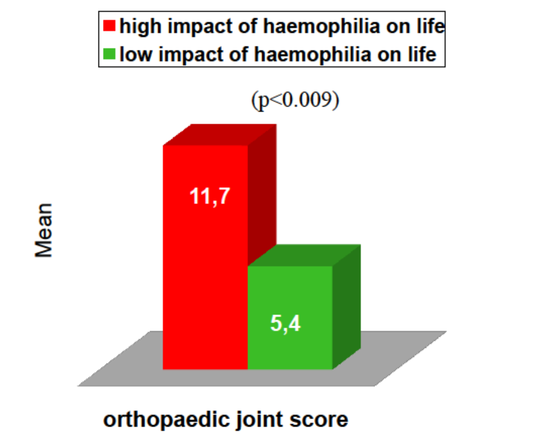

Figure 2: Orthopaedic joint status in patients with high versus low impact of the disease

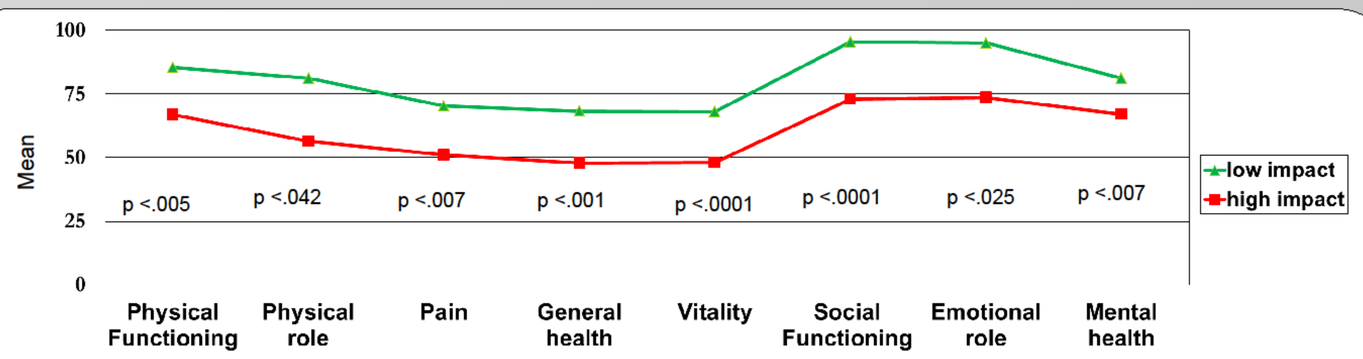

Figure 3: Quality of Life (SF-36) between patients with bleeding disorders with low vs. high impact of the disease

Conclusion

Despite good availability of clotting factor concentrates, bleeding disorders still have a major impact on the patients' lives. The perceived impact of bleeding disorders on patients' lives seems to have a stronger impact on treatment outcomes than the patients' actual social status.

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References:

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