Poster W-P-174

Caregiver Burden of Parents of Children with Haemophilia – Results form a Single UK Centre

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Introduction

- The standard treatment of boys with haemophilia in the UK is prophylaxis, where treatment commences following the first bleeding episode aiming to establish 'full' prophylaxis with a measurable trough as soon as venous access allows [1]. Parents of a child with haemophilia require specific skills such as bleed recognition and treatment administration [2].
- Caregivers' often face limitations in their life leading to perceived burden. This burden of disease management can lead to psychological (stress and coping [3], anxiety and depression, stigmatization and discrimination [4]) as well as economical concerns for the parents [5]. How this treatment burden of parenting a child with haemophilia impacts on caregivers quality of life is not yet examined. It is expected that being a parent of a child with haemophilia will influence their quality of life mostly because they will worry and have fears related to the well-being of their child.
- This single centre study describes caregivers' burden and investigates how caregivers' burden affects parents' health-related quality of life (HRQoL).
- The study was sponsored by Baxter.

Methods

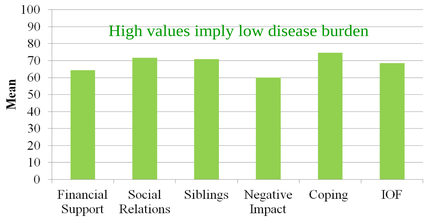
- Caregivers of children aged 8-17 years with haemophilia A or B of any severity, with current or past inhibitor were included in the study.
- Questionnaires for caregivers comprised demographic data, self-reported generic HRQoL (EQ-5D [6], SF-36 [7]) and caregiver burden (IOF: Impact on Family Scale [8]) instruments.
- Children were asked about their HRQoL (EQ-5D-Y [9], Haemo-QoL short version [10]).
- Consecutive parent/child dyads were approached at routine clinical reviews; 20 dyads participated in the study.

Results

- 75% of caregivers were mothers with a mean age of 39.8±6.2 years (range 28-52), 25% were fathers with a mean age of 44.22±7.4 years (range 34-62). Children had a mean age of 11.6±2.4 years (range 8-17).
- 95% of caregivers were working part- or full-time; 40% of those working part-time were doing so because they were taking care of their haemophilic child.
- The majority reported that haemophilia causes an economic impact on the family (55%).

- 16 boys had haemophilia A (80%), 4 had haemophilia B (20%)
- 12 boys had severe haemophilia (60%), 4 moderate (20%) and 4 mild (20%)
- 16 boys were treated with prophylaxis with various dosing regimens (9 boys were on primary prophylaxis)
- 17 were on home treatment (85%) and 8 usually self-infused (40%)
- 5 boys had had an inhibitor; 1 was still on daily immune tolerance and had a central venous access device in situ
- Children had an average 0.3±0.6 bleeds (range 0-2) in the previous 3 months

Caregivers' Burden (IOF)

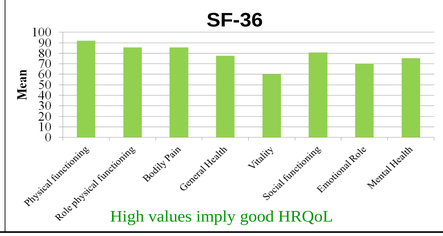


Caregivers showed highest impairments in the dimension 'negative impact' and mainly

- *"worried about what will happen to their child in the future"* (65%)
- *"were thinking about not having more children because of the illness"* (44.4%)
- *"were wondering sometimes whether their child should be treated 'differently' or the same as a normal child"* (35%)

Health-Related Quality of Life

SF-36



EQ-5D

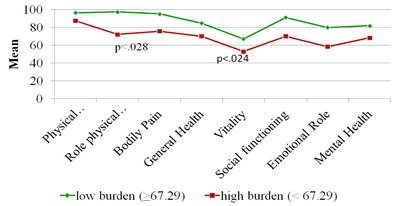
Caregivers reported on the
- EQ-VAS (M=82.16±14.8)
- EQ-5D (M=0.90±0.1)

Children reported on the
- EQ-VAS (M=90.25±10.1)
- EQ-5D (M=0.81±0.3)

Haemo-QoL

Children reported on the
- Total score (M=22.62±16.3)

Impact of Caregivers' Burden on HRQoL



- In the **EQ-VAS** there was a significant difference (p<.034) between caregivers with low (M=88.80±10.1) and high disease burden (M=74.78±16.1)
- In the **EQ-5D** there was no significant difference between caregivers with low and high burden due to their son's disease

Conclusion

More significant differences were found between caregivers who reported that haemophilia has an economic impact on the family; there showed differences in their perceived burden in the domains 'financial support' (p<.008), 'social relationships' (p<.042) and 'the total IOF score' (p<.033) and in their HRQoL in the social domains of the SF-36 'social functioning' (p<.002), 'emotional role' (p<.043) and 'mental health' (p<.009) as well as for the PSC summary score (p<.027).

Perceived burden of haemophilia has a direct impact on caregivers HRQoL. Further studies with haemophilia-specific instruments are needed to verify these findings.

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