Understanding the Impact of Hemophilia on the Family: A Pilot Study of the PedsQL-Family Impact Module

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INTRODUCTION

-The impact of disease on the family is a an important consideration in pediatric chronic disease.

- The Canadian Hemophilia Outcomes-Kids Life Assessment Tool (CHO-KLAT) is a disease-specific quality of life tool that measures quality of life in children with hemophilia (Young et al. 2004)

- The PEDsQL Family Impact module has been validated for many chronic pediatric conditions, but has not been applied to the hemophilia population.(Varni et al. 2004)

STUDY OBJECTIVE

To apply the PedsQL-FIM to parents of children with hemophilia and correlate the scores with CHO-KLAT scores.

METHODOLOGY

-44 parents of children with all severities of hemophilia (19 severe, 14 moderate and 11 mild) completed the FIM and CHO-KLAT questionnaires.

- The FIM Questionnaire contained 36 items divided into 6 categories of parent functioning and 2 categories of family functioning.

- ANOVA was used to compare FIM scores between groups.

Table 1: PedsQL™ Family Impact Module – general content of scales

Parent Functioning	# Items	General Content
Physical Functioning	6	Problems with physical functioning, including feeling tired, getting headaches, feeling weak, and stomach problems
Emotional Functioning	5	Problems with emotional functioning, including anxiety, sadness, anger, frustration, and feeling helpless or hopeless
Social Functioning	4	Problems with social functioning, including feeling isolated, difficulty getting support from others, and finding time or energy for social activities
Cognitive Functioning	5	Problems with cognitive functioning, including difficulty maintaining attention, remembering things, and thinking quickly
Communication	3	Problems with communication, including others not understanding the family's situation, difficulty talking about child's health condition, and communicating with health professionals
Worry	5	Problems with worrying, including worrying about child's treatments and side effects, about others' reactions to child's condition, about the effect of the illness on the rest of the family, and about child's future
Family Functioning	**# Items**	**General Content**
Daily Activities	3	Problems with daily activities, including activities taking more time and effort, difficulty finding time and energy to finish household tasks
Family Relationships	5	Problems with family relationships, including communication, stress, and conflicts between family members, and difficulty making decisions and solving problems as a family

Total Score is computed by averaging all 36 items. Parent HRQOL Summary Score is computed by averaging 20 items in Physical, Emotional, Social, and Cognitive Functioning. Family Summary Score is computed by averaging 8 items in Daily Activities and Family Relationships.

RESULTS

-The FIM scale correlated well with the CHO-KLAT scores (r= 0.64, p<0.001).

- Mean FIM score across domains(83.1 +/- 18.2) compared to mean FIM scores between severity groups using ANOVA did not show any significant differences.

- When patients were grouped clinically (considering need for regular infusions and prophylactic treatment), the social functioning FIM scale neared significance (p=0.06)

-When patients were grouped by functional status as determined by physical assessment, only 2 patients had severe deficits. Parents in this group had substantially lower total FIM scores (43.3 and 44.4) and scores were most disparate in the sub-domain of emotional function.

DISCUSSION

-Results suggest that regular infusions and bleeding may impact the family, as the social functioning score neared significance.

-The lack of significant differences found between the mild, moderate and severe groups may be due to the high rate of prophylaxis in our population.

-The sample size in this study was small, addtional testing with a larger sample size is needed to confirm these results.

CONCLUSION

-Overall, the parental PEDsQL-FIM scores correlated with the CHO-KLAT scores

- Further analysis should involve a larger sample size and consider clinical issues that contribute to the burdens of the disease.

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