

Children and adolescents with type 1 diabetes mellitus

Family dynamics and health-related quality of life after diabetes onset

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ABSTRACT

Aim: The main aim of this thesis was to explore different aspects of family dynamics and health-related quality of life (HRQOL) after the onset of T1DM in children and adolescents. A second aim was to evaluate the effects of a two-year prospective family intervention randomized controlled trial (RCT) with additional psychological support after the onset of T1DM, focusing on facilitating communication skills within the family in the initial and ongoing diabetes care.

Methods: In Paper I, children and parents completed the Swedish versions of the PedsQL 4.0 and PedsQL 3.0 questionnaires measuring generic and diabetes-specific HRQOL, respectively. In Paper II, 30 parents and eight siblings participated in focus group discussions and individual interviews about their preconceptions about diabetes, their reactions to the child's diagnosis of T1DM, and its impact on family relationships. Papers III and IV examined different aspects of the two-year family intervention study in which children aged 3–15 years, recently diagnosed with T1DM, participated with their parents. In this RCT, two different treatment regimens at T1DM diagnosis were compared. The treatment-as-usual regimen provided support from the whole diabetes team except for the specific support of a family psychologist-psychotherapist with special training in diabetes. Families in the intervention group were also provided with therapy focusing on improving communication.

Results: In Paper I, the Total Score of the PedsQL 4.0 Generic Core Scales and the PedsQL 3.0 Diabetes Module exceeded the criterion for satisfactory internal consistency, for both child self-reports and parent proxy reports (α -values >0.88). In Paper II, fathers showed more uniform emotional and behavioral patterns than mothers did. Among mothers, more distinct differences appeared, depending on the age of the child with T1DM and the civil status of the mother. Siblings reported increased demands on them in terms of greater responsibility and maturity. Reactions such as competition and jealousy occurred at younger ages, whereas older siblings were more caring but also carried an increased burden of worry. In Paper III, a higher education level in the father was associated with a lower HbA1c level in the child. Furthermore, in Paper IV, at 24 months the children and their fathers in the intervention group rated the child's diabetes-specific HRQOL as significantly better and the child's worry as lower compared to the control group. Communication skills improved significantly over time in the intervention group.

Conclusion: The two-year prospective family intervention study showed promising results. The children in the intervention group showed several indications of improved generic and diabetes-specific HRQOL. Actively involving both parents, not only immediately after T1DM onset but also during two years of ongoing care, had a positive impact on the children's and adolescents' HRQOL.

Keywords: health-related quality of life, children, adolescents, type 1 diabetes, families, parental education, family dynamics, glycemic control, family intervention.

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- I. Sand P, Kljajić M, Schaller J, Forsander G. The reliability of the Health Related Quality Of Life questionnaire PedsQL 3.0 Diabetes Module™ for Swedish children with Type 1 diabetes. *Acta Paediatrica* 04/2012; 101(8):e344-9.
- II. Sand P, Dellenmark Blom M, Forsander G, Sparud Lundin C. Family dynamics when a child becomes chronically ill: impact of type 1 diabetes onset in children and adolescents. Submitted for publication.
- III. Sand P, Kleiberg Nilsson A, Forsander G. Paternal Influence on Glycemic control at Baseline and One Year Post Diagnosis in Children and Adolescents with Type 1 Diabetes Mellitus. *Diabetes Research and Treatment*, Open Access 12/2014; 1(4):1-6. DOI: 10.14437/DRTOA-1-115.
- IV. Sand P, Kljajić M, Forsander G. Improved health-related quality of life in children and adolescents with type 1 diabetes: a two-year prospective family intervention RCT study. Submitted for publication.



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