Conclusion

The family is affected during the first year after their child is diagnosed with type 1 diabetes. Both parents and the youngest children estimated a high degree of worry and mothers’ health-related quality of life, especially in their emotional functioning are affected during the first year after diagnosis. The diabetes team need to be aware of this and take it into consideration.

Method

Sixty-nine children and their parents were included in the study. Parents independently filled in the PedsQL™ Family Impact Module and PedsQL™ Health Care Satisfaction generic Module. At follow-up one year later the same questionnaires were administrated added by PedsQL™ 3.0 Diabetes Module addressed to both parents and children over 5 years of age (n=56).

Objectives

When a child is diagnosed with type 1 diabetes it is a complex and challenging situation for the whole family and they need to change their daily life. The management of the disease places substantial demands on the family and they need to change their daily life. The impact on the family in short and long perspective is rarely described, therefore the aim of this study was to describe the impact on the family from the perspectives of parents and children and in terms of health-related quality of life at diagnosis and one year after the child was diagnosed with type 1 diabetes. A further aim was to describe the parents’ satisfaction with the care received.

Results

Mothers described a lower health-related quality of life than fathers both at the time for the child’s discharge (p=0.003) and one year later (p= 0.041). In diabetes-specific health-related quality of life children aged 5-7 years and their parents reported more worry than children and parents in older age groups (p=0.037). Children aged 8-12 and 13-18 years reported a higher treatment adherence compared to mothers (p=0.011 and p=0.039 respectively), no differences were found between children and fathers. Both parents expressed overall satisfaction with the child’s healthcare.