

Diabetes and Down's syndrome; Psychosocial health, family dynamics and challenges in diabetes self-care

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"We are much more, how should I put it, restricted than we would have been if we had had a "normal" 19-year-old or a 19-year-old without diabetes. Down's syndrome is not really a big problem."

Aim

The aim of the study was to examine psychosocial health, family dynamics and challenges in keeping a good glycaemic control in children, adolescents and young adults with Down's syndrome and diabetes.

Scientific questions

1. How does diabetes diagnosis affect psychosocial health and family dynamics in children/ adolescents/ young adults with DS?
2. What challenges are there in keeping a good glycaemic control in a child/ adolescent/ young adult with diabetes and DS?

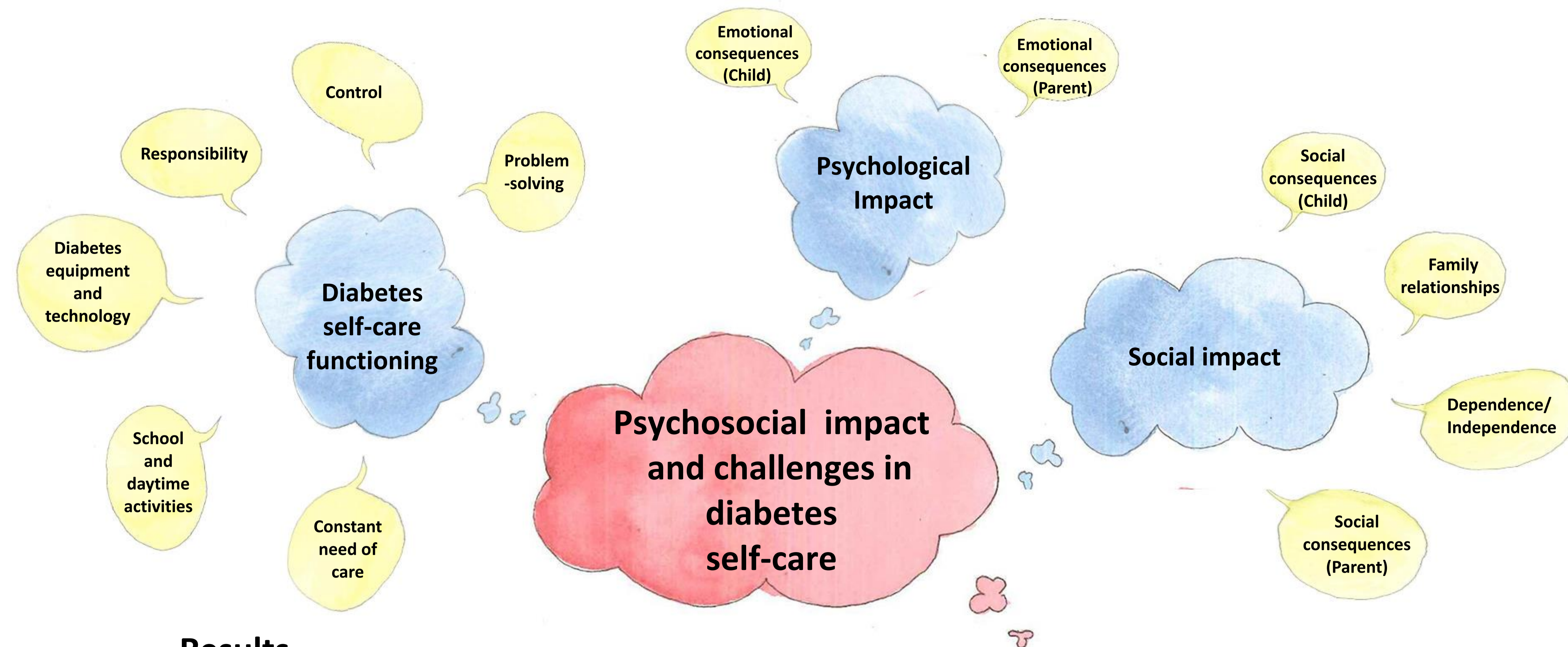
Methods

Participants

11 parents (6 mothers, 5 fathers) of 6 children (12-22y) with Down's syndrome and diabetes participated in the study.

Data analysis

A semi-structured interview guide was constructed for the interviews. These were audiotaped, transcribed and analysed by using qualitative content analysis; a method for systematic analysis of interview texts in various steps. The qualitative content analysis used was influenced by Graneheim and Lundman.



Results

The figure above provides an overview of the main theme, categories and subcategories that emerged in the analysis. Most prominent in our results was the social impact of the diabetes diagnosis. The social consequences involves the young individual as well as his/ her family. For the child/ adolescent/ young adult the reason for the social restrictions were mainly their need of continuous help with the diabetes self-care.

Diabetes care requires a lot of time and attention from the parents. Feelings of guilt towards siblings were brought up in many of the interviews. The diabetes care sometimes was a cause of conflict between the parents but also fulfilled a task that made them strong as a team.

Conclusions

The social consequences of diabetes diagnosis in children, adolescents and young adults with Down's syndrome are the most prominent in our results. The diabetes diagnosis cause continuous need for help and support in a lifelong perspective and thus affects these individuals in terms of social restrictions and less prospects of independency

"Without her diabetes it would not be a problem if she slept over at a friend's or went on a camp, she wouldn't really need an assistant. She would be much more independent."