



Experiences with a group intervention for adolescents with type 1 diabetes and their parents

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Introduction

Puberty and adolescence can be a difficult time for families in which there are children with diabetes. The relationship between the parents and the adolescent may become strained at this time, when there are many other issues at play in people's lives.¹

At least two factors characterise the transition from being a child to becoming an adolescent. The first is their physical development, with regard to the hormone changes of puberty. The second is their cognitive development; adolescents begin to think abstractly and analyse theoretical problems in a different way.²

In 2004, the Child and Adolescent Psychiatric Department

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Abstract

Background: Increased adolescent-parent engagement in diabetes-related tasks appears to decrease diabetes-related family conflict. Group intervention may be a good approach when caring for adolescents with chronic conditions, including diabetes.

Aim: This article aims to describe how group intervention may be useful in the treatment of adolescents with type 1 diabetes. When these children enter puberty and become adolescents, it can become difficult. In many cases, family-related conflict has a negative impact on an adolescent's blood sugar levels and self-care behaviour. *Method:* 19 adolescents (age 13–17 years) and their parents participated in group intervention. Families were recruited from outpatient clinics in two centres in Middle-Norway. Separate groups met once a month for 1 year. All adolescents and parents completed a battery of self-report measures. In addition, HbA_{1c} values were obtained five times from the adolescents' medical records.

Results: In terms of metabolic control there was a significant decrease in HbA_{1c} values in the girls studied. In adolescents of both sexes, the process of deterioration was stopped.

Conclusion: The development of efficient interventions for this group of patients is highly needed. Our intervention was peer-oriented and psycho-educative. Although the sample size in this study was small, one may still consider that group intervention may improve parent-adolescent relationships. Results from the study also demonstrate that group intervention may improve metabolic control in girls, without deterioration in health-related quality-of-life.

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Key words

Diabetes; adolescents; parents; group intervention

(BUP), the Children's Out-patient Clinic at Levanger Hospital and the Children's Out-patient Clinic at Namsos Hospital, Norway, co-operated on a project called Preventing late complications of diabetes in adolescents with Insulin dependent Diabetes Mellitus type 1 (IDDM), a group-based re-education and communication training for adolescents and their parents. The results from this study have been described in detail.³ The project was born from our experiences as diabetes nurses at our outpatients' clinic. Three elements stood out: the amount of information and knowledge present in some families which was not communicated to others; the quantity and intensity of arguing and disagreements between adolescents and their parents concerning how to treat diabetes; diabetes is often poorly regulated in this patient group, and some adolescents find it extremely difficult to get their blood sugar down to an acceptable level.

Parent involvement and increased adolescent-parent engagement in diabetes tasks appears to decrease diabetes-related family



conflict.⁴ With the present intervention we hoped to encourage better communication between adolescents with diabetes and their parents, and to promote co-operation between them. A study in Bergen, Norway, showed that parent care and involvement are important factors for the health and well being of adolescents with diabetes, and emphasised the importance of the family approach in diabetes care.⁵ In addition, peergroup meetings may have a positive effect on blood sugar levels in adolescents with diabetes.^{6,7} Data also suggest that problem solving in groups may be more effective than traditional follow-up.6,7 The basic idea of group work is that the participants may help both themselves and each other by sharing information and feelings, and comparing attitudes, behaviour and experiences.8 Our hypothesis was that peer support and the opportunity to solve problems in groups would improve glycosylated haemoglobin (HbA_{1c}) values in these adolescents, without reducing quality-oflife. We hoped that the adolescents and their parents would work as a team in the treatment of diabetes, and that gradually this would encourage the adolescents to take on more responsibility. The parents, in their own groups, would have the opportunity to exchange experiences and give each other support and encouragement.

Re-education was implemented in the adolescent groups, designed by nurses based on the paediatric ward, who specialised in diabetes. The adolescents brought their own experiences to re-education. We wanted the parents to trust that their adolescents had the information necessary to be able to treat their diabetes, to a certain extent.

This article aims to describe the elements of our intervention, and to communicate our experiences.

We want to show why this is a good approach when caring for adolescents with chronic illnesses and their parents.

Methods

Participants

Sixty adolescents (age range 13–18 years) with type 1 diabetes were attending follow-up checkups at the Levanger and Namsos Hospitals before the intervention started. Trial recruitment was undertaken through conversations at the outpatient clinics and through letters. Adolescents and parents all received written invitations to participate in the project. The adolescent and at least one parent were required to participate; this disqualified some of the parents who were interested in participating.

Everyone who signed up to participate in the project was interviewed before the group work started. Interviews, which were conducted at the out-patient clinics and over the telephone, focused on their daily life with regard to one or more family members having diabetes, their expectations of the project and clarification of information. Parents and the adolescents were interviewed separately. The adolescents were divided into three groups. Due to geographical distance, one group was formed in the northern part of the county; the remaining participants were randomly divided into two groups.

A project information meeting was held for the invited families who wanted to participate in the project, which was attended by representatives from the paediatric ward and the BUP.

Two groups started group work in March, among them the group from the Northern part of the county. The control group began group work in June. The only difference between the control group and the other two groups was that the control group attended group meetings six times, whereas the other two groups attended 10 group meetings.

Parents were also divided into three groups and started group work at the same time as their adolescents. All groups met once a month, for 1 hour.

Instruments

The Diabetes Quality-of-Life Questionnaire (DOOL) was used for both the adolescents and their parents. This questionnaire had previously been used in the Group Hvidore Study on Childhood Diabetes,⁹ as well as in other studies, and has been modified for use with adolescents.¹⁰ The DQOL measures diabetes-related impact, daily and future diseaserelated worries and diabetes life satisfaction. Participants completed the questionnaire four times: before they started attending group meetings, four months after they began attending group meetings, during December 2004 and in December 2005.

This project also measured HbA_{1c} values. Blood samples were tested using a DCA-2000 analyser (Bayer Corp, Elkhart, IN USA). These blood samples are routinely taken every three months, therefore the values were obtained from the medical records of participating adolescents.

Treatment programme

In the life of a group, at least four different phases occur: the development phase, the formation phase, the working phase and the termination phase.⁸

Development phase: Before group meetings started, much time was invested in planning the project, which was specifically designed for the intended group (namely, families with one or more members who had diabetes). In line with what



Heap refers to as a 'diagnostic awareness',⁸ we reflected on how this project and its results would affect those involved. The development phase also included theories about group methods and communication.^{8,11,12} John Hodge's principles regarding group leadership¹³ were used in the planning process. *Formation phase*: This phase was characterised by exploring and seeking commonality.⁸

A contract was drawn up at the first group meeting that included the following topics:

• Confidentiality – required of all group members regarding everything that was said and done during group sessions;

• Verbal and physical abuse – hurting another group member was forbidden;

• Absenteeism – the group leader must be notified of absenteeism as soon as possible.

Re-education was an important aspect of this project. Although some participants had had diabetes for many years, others had little experience as patients. Table 1 provides a full overview of re-education strategies used.

Working phase: Each meeting started with a warm-up activity such as painting, movement/exercises, or a round of questions about topics that were not related to diabetes. After the warm-up we sat in a circle without a table, and a stone was sent around the circle to each participant. The use of a stone was not deliberate - it could have easily been a ball or a toy - but the meeting topic was often established during this round. Meetings were also closed by sending the stone around. We then summarised each meeting and briefly spoke about the next meeting.

Termination phase: This project phase should be seen by the participants as an expected and natural time to end the project. For this to

occur smoothly, the group leaders need to prepare the participants.

Project collaborators

A team of nurses, medical doctors and a trained social worker were involved in this project. They were recruited from the pediatric outpatient clinics in Levanger and Namsos, and the BUP in Levanger. Group leaders attended evaluation meetings before and after each group session.

Data analysis

Statistical analyses of the data were performed using SPSS Version 13.0 (SPSS Inc., Chicago, IL, USA). Means (with 95% confidence intervals based on a normal distribution) were computed for the measurements of metabolic control. The effect of the intervention was tested by paired-sample *t*-tests for the whole sample and for each gender. Statistical significance was set at $0.05.^3$

Ethics

The study was approved by Regional Ethics Committee. Written informed consent was obtained from all participants before entry. The consent form stated that by agreeing to participate in the project, the project leader was permitted to access the HbA_{1c} values included in the adolescents' medical records.

Results

Nineteen adolescents (31.7% of target group; 10 girls [52.6%] and nine boys [47.4%]) agreed to participate in the project, including two pairs of siblings. Duration of diabetes illness in these adolescents ranged from 1 to 15 years (mean duration 6.6 years). The participants were between 13 and 17 years of age. Eight adolescents (42%) were included in the control group, five in one treatment group and six in the other.

HbA_{1c} values

The HbA_{1c} values recorded in each adolescent's medical notes were collected five times between January 2004 and December 2005. Across the total group, a non-significant decrease in mean HbA_{1c} value, from 9.2% to 8.7% was observed from baseline until the 24-month follow-up. The boys' (n=9) mean HbA_{1c} value increased from 8.9% to 9.2% whereas the decrease was significant in the mean value for girls (n=10), from 9.4% to 8.4% during the study period (p= 0.039).³

The observed reduction in the girls' mean HbA_{1c} value is of clinical significance; however, the small sample size in this study must be taken into consideration when interpreting the results. There were no notable differences in HbA_{1c} levels between the groups that started therapy first and the control group.

The questionnaires did not give us clear answers. Indeed, responses varied to such an extent that it was difficult to evaluate, from the questionnaires, whether the families felt that their situations had improved after group intervention.³ Results based on interviews with the participants, however, demonstrated that these interventions improved parent-adolescent relationships.

Discussion

The group sessions were intended to be a supplement to regular, individual, consultations, which give a client the opportunity to raise personal issues that may be uncomfortable to discuss in a group setting.¹⁴

We consider that this intervention had five successful aspects, the first of which was co-operation. Through co-operation between the paediatric out-patient clinics and the BUP, group participants could benefit from the input of the vari-

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Торіс	Details of content
Me and my diabetes	Each person talks about him/herself
What is diabetes?	Physiology (group discussion)
Measuring blood sugar levels	When and how Alternative testing places on body Blood sugar profile Blood sugar measuring equipment, comparison and demonstration The importance of changing places to inject insulin Adolescents' own experiences
Insulin	Insulin types and functions New insulin types Discussion about what each group member uses Information about new insulin
Hypoglycaemia	What happens in the body/symptoms Own experiences of group members Treatment of severe hypoglycemia /information letter about hypoglycemia
Diabetic ketoacidosis	Group members participate with own experiences Information about diabetic ketoacidosis
Alcohol/smoking	Information sheet Group members' experiences
Physical activity/sports	Group members' experiences Information about the importance of physical activity Bowling and swimming trips
Diet	How various foods effect blood sugar Overeating/greater need for insulin Learning by doing: eating different types of sweets, food and drink, and measuring blood sugar levels
Various aids for injecting insulin	Insulin pump Insulin pens
Using the internet to obtain diabetes information	Everyone uses their own PCs to do this Group leaders assist in finding relevant information on the internet
The latest research	Group leaders answer questions from group members and give information on the latest research about diabetes type 1
Travelling/longer stays abroad/ living on one's own	Group members tell about their own experiences and thoughts about these issues
Late complications/HbA _{1c} values	Group leaders discuss this difficult issue, taking into consideration the age of the participating adolescents

Table 1. Re-education strategies for adolescents with diabetes and their parents



ous professionals based within these departments. This is a vital aspect which can be used to better the service we give this patient group.

Secondly, the group leaders were equal members of the groups, not teachers. One reason for starting the project was that we had seen how some adolescents and their parents possessed much information and experience, which could be shared with others in similar situations. The group leaders wove the knowledge and experience of the participants together with the theory. Such a process enhanced the usefulness of the information, both for participants but also on an ongoing basis for group leaders, as they continue working with new individuals in this patient group.

Thirdly, we had enough time. Planning a project such as this is of benefit to all those involved, as well as those who wish to implement similar projects. It is essential for this type of project that everyone involved has the necessary time for proper development and evaluation of its content. Having wellplanned group sessions is vital, especially when one is trying to get adolescents with diabetes to attend group meetings. This also entails that colleagues and advisors donate their time to give support and input.

Fourthly, the sessions had variety; there were no dropouts during the project period. The group sessions included theory and enjoyment, which maintained the adolescents' interest. Warm-up exercises were appreciated by most, and were requested. Swimming, bowling and making food together were part of the project.

Finally, the group leader was a specialist in group therapy, which helped to achieve optimal results in group sessions. The group members were very different from one

another; in some cases their only common ground was their illness. The group leaders were responsible for each member of the group feeling safe and providing everyone with the opportunity to participate to the best of his or her ability.

It is important for the future health of adolescents with diabetes that the adolescents, their parents and health care workers co-operate.³ Parents are a source of care and understanding for their adolescents; they are experts regarding their child and their child's needs and resources. Health care workers have general knowledge about illness, symptoms and treatment, and should be offering solutions other than the traditional follow-up consultations at out-patient clinics. In our opinion, co-operation between the paediatric and BUP departments was necessary in order to serve children and adolescents with chronic illnesses in an adequate manner.

Our experience from this project has shown that group intervention is a good way to take care of the parents of adolescents with chronic illness.³ It is emotionally and intellectually productive for the parents to discuss their experiences with other parents who are in similar situations, with a health care worker present. Group leaders have an important function in these settings: they facilitate events by ensuring that everyone gets the time and opportunity to contribute.¹²

Re-education was useful for everyone. The parents needed to know that their adolescents had updated information.

In evaluating the group sessions we consider that 1 hour sessions may not provide enough time, especially for the parent groups. For future interventions of this kind, group sessions that last $1\frac{1}{2} - 2$ hours should be considered.

An interesting research topic for the future is why HbA_{1c} values decreased so much in the girls. During the group sessions we saw that the boys participated to a greater extent and were more eager to attend the group sessions. In addition, it was the boys who showed up early to chat with group leaders before the sessions started. Williams found that adolescent girls and boys with diabetes lived with their disease very differently.¹⁵ Other studies indicate that girls with diabetes report lower life satisfaction and health perception than boys.^{16, 17} Related to this are studies that show both eating disorders and emotional disorders to be more common among young women with diabetes.¹⁸

We did not get positive results from the quality-of-life questionnaire.³ Retrospectively we can see that other studies targeting adolescent-parent relationships would be helpful in identifying better instruments. For example, Wysocki and colleagues reported that participants in their study had improved parent-adolescent relationships.¹⁹ Other studies have shown that family involvement may be useful in the treatment of adolescents with type 1 diabetes, and that emotional involvement by parents is associated with good glycaemic control.^{20,21}

Irregular attendance in the parent groups was a problem, and in the future more work must be put into emphasising the importance of continuity and attendance. It is also noteworthy that more mothers than fathers attended group meetings. Previously, Stevenson concluded that mothers showed more accurate appraisal of their child's diabetes than fathers.²¹

Conclusion

The project was a success, and both paediatric out-patient clinics in

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Nord-Trøndelag are proceeding with new groups. We hope in the future that we can offer these kinds of informative, constructive and enriching group sessions for families with children who have other types of chronic illnesses. Outside the guidelines of the present study it will not be necessary for both adolescents/children and their parents to participate, which would open the door to a wider group of interested participants.

We observed a significant decrease in HbA_{1c} values in girls and, in both girls and boys, the process of deterioration halted.³ These observations are worthy of further investigation.

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