

Title

Development of an acceptable and feasible self-management group for children, young people, and families living with Type 1 diabetes

Running head: A self-management group for young people and families with T1DM

Authors

Ran Alice Cai

UCLH NHS Foundation Trust Child and Adolescent Psychological Services

Richard IG Holt

Human Development and Health Academic Unit, Faculty of Medicine, University of Southampton, Southampton, UK

Lucy Casdagli,

UCLH NHS Foundation Trust Child and Adolescent Psychological Services

Russell M. Viner

UCL Institute of Child Health, London

Rebecca Thompson

UCLH NHS Foundation Trust Paediatric and Adolescent Diabetes Service

Katharine Barnard

Faculty of Health and Social Science, Bournemouth University

Deborah Christie*

UCLH NHS Foundation Trust Child and Adolescent Psychological Services

* Corresponding Author E-mail: Deborah.christie@uclh.nhs.uk

Word count: 3,615

Funding

This project was funded by a grant from the Diabetes Research Wellness Foundation

Competing interests

None declared.

Acknowledgement

We would like to thank the young people and families that took part in the development of the intervention and participated in the focus groups. We would also like to thank Dr Hannah Duncan, Madeline Harris, Louise Potts, Emily Storr and Laura Rose for helping to run the groups.

Novelty statements

- This study developed an intervention to help children with Type 1 diabetes and their parents improve recognition of hypoglycaemia and hyperglycaemia and reflect on experiences and choices about when and how to put diabetes knowledge into practice.
- The intervention encourages parents and young people to see themselves as experts in their diabetes and allows young people to demonstrate diabetes knowledge.
- It is important to offer parents and young people the chance to learn diabetes-related information from each other.

Abstract

Aims This study developed an acceptable and feasible self-management intervention that addresses the self-identified needs of children and young people with Type 1 diabetes and their parents.

Methods Phase 1 reviewed previous interventions and interviewed the clinical team, young people, and families. Phase 2 ran three age-matched focus groups with 11 families of children 8-16 years old. Feedback was used to modify the workshop. Phase 3 evaluated feasibility of delivery, as well as the effects on metabolic control, quality of life, and fear of hypoglycaemia measured at baseline and 1-3 months post intervention.

Results Eighty-nine families were invited to take part. Twenty-two (25%) participated in seven pilot groups (median age of young people 10 years, 36% girls). The intervention comprised a developmentally appropriate workshop for young people and parents addressing a) blood glucose control, b) potential impact of long-term high HbA_{1c}, c) Effects of “hypos” and “hypers”, d) self-management techniques, and e) talking confidently to people about diabetes. Participants were enthusiastic and positive about the workshop and would recommend the workshop to others. Young people liked sharing ideas and meeting others with diabetes, while parents enjoyed listening to their children talk about their diabetes knowledge.

Conclusions Families living with Type 1 diabetes participated in developing a self-management group intervention. Although we demonstrated acceptability and feasibility, the pilot study results do not support the development of a randomised control trial to evaluate the effectiveness in improving HbA_{1c}.

Introduction

Hypoglycaemia is the commonest adverse event associated with insulin treatment in both Type 2 and Type 1 diabetes [1]. Hypoglycaemic episodes are not only physically aversive and dangerous, but cause social embarrassment for children and adolescents. As a result, fear of hypoglycaemia in both parents and young people can potentially lead to two problems [2]. One is reduced quality of life underpinned by anxiety about the unpleasantness of “hypos”, the relentless nature of daily management, and a lack of confidence that others are able or willing to provide appropriate care [3]. The second is ‘hypoglycaemia avoidance behaviours’ [1], aimed at preventing low blood glucose. These can often be maladaptive, such as eating large snacks or allowing hyperglycaemia as a precaution.

The subsequent rise in glycated haemoglobin (HbA_{1c}) as a consequence of these short term coping responses worsens the risks of long-term complications [1]. Interventions to support children with Type 1 diabetes (T1DM) and reduce fear of hypoglycaemia are needed. [3]. There is an extensive literature on programmes designed to address general regimen adherence in children and adolescents with T1DM [4,5], but little has been published on interventions specifically for parents of children with T1DM. Recently evaluated structured educational programmes have focused on increasing knowledge and skills, and offering practical ways to reduce HbA_{1c} and hyperglycaemia; however, behaviour change strategies that focus on fear of hypoglycaemia are not specifically addressed [6,7]. Moreover, in a previous systematic review [8], no interventions were found that focus specifically on reducing parental fear of hypoglycaemia that might mediate or moderate the ability of parents to put education and knowledge into practice.

We therefore undertook a project aimed at 1) developing an age-appropriate programme that addresses the self-identified needs of children and young people with T1DM and their parents in relation to hypoglycaemia and blood glucose management; and 2)

assessing the acceptability (usefulness and enjoyableness for young people and their families) and feasibility of delivering the programme as a pilot undertaken within a clinical service.

Methods

We undertook our study in three phases, the first two developing and refining the intervention and the third evaluating a pilot of the intervention. Ethics approval was received from NRES Committee London-Hampstead.

Development

Phase 1: The research team identified key themes from their clinical practice and integrated them with themes identified in the literature and a recently evaluated structured education programme [9]. The suggested intervention was a 4 session family programme run once a month that would focus on managing hypoglycaemia.

Five children and young people attending the Child and Adolescent UCLH Diabetes clinics (median age 10 years, range 9-16; median duration of diabetes 4, range 2-13) and their parents were approached. Feedback from these interviews indicated that families wanted a single group run over a day and that the content should not be too new or complicated. Young people and parents were clear that they did not want to attend a workshop that focused on fear of hypoglycaemia but wanted to use the time to address annoyance and practicalities of diabetes self-management.

Phase 2: The intervention content and structure was redesigned using these ideas to be run over a single day and focused on overall blood glucose management and the effects of diabetes on daily life. Ideas from the blood glucose awareness training programme were used to inform the workshop content which included family group sessions on: a) how insulin and food affect blood glucose; b) potential impact of long-term high HbA_{1c}; c) effects of hypoglycaemia and hyperglycaemia on daily living; d) self-management techniques; and e) talking to people about diabetes with confidence.

Children, young people, and families (including those who had been previously interviewed) were then invited to review the draft intervention. Three focus groups were run with different age groups: one for four adolescents (14-16 years old) and four mothers, one for three children (10-11 years old), two mothers, one father, and one brother, and one for four children (8-10 years old), four mothers, and one sister. Transcriptions were made from audio recordings of the three groups. Feedback was discussed by the clinical intervention team (DC, LC, and RC) and further amendments were made.

Delivery of the Pilot study (Phase 3)

Families with children and young people aged between 8 and 16 years old with T1DM were contacted by phone or approached in clinic. Families who agreed to participate were offered a group based on the young person's age and gender. Reasons for non-participation were recorded in order to learn about barriers to participation and ensure equitable access. We used a mixed models approach to evaluate the feasibility of delivery, recruitment rates, interest in participation and effectiveness of the intervention and generate data to inform a full randomized controlled trial (RCT).

The intervention

The pilot intervention workshops were delivered by two clinical psychologists, a diabetes clinical nurse specialist and an assistant psychologist. **Table 1** shows a summary of the different activities that were included.

Most of the day young people and parents worked together. In the session after lunch the young people and parents were in separate groups each facilitated by a qualified clinical psychologist. The underlying philosophy of the intervention approach came from systemic theories which assume families are aware of what they 'need' to do; however, they are not willing, able or ready to put this knowledge into practice. 'Scaffolding' questions help 'draw information out' [10]. Learning is a collaborative effort between family and provider reducing the sense of an expert imposing knowledge, moving towards a shared venture. This

active rather than passive approach is effective at eliciting behaviour change in other areas [11]. We also incorporated evidence based techniques designed to engage young people in wanting to change their behaviour [12,13].

Participants

Eligible participants were between 8-16 years old, at least 6 months post diagnosis with no additional co-morbid conditions and sufficient spoken English to participate in the groups.

The Paediatric and adolescent diabetes service at University College London Hospital (UCLH) has approximately 400 children with T1DM, of whom approximately 300 were eligible to participate in the pilot. Twenty-five participants were required to achieve pilot and feasibility objectives. Estimating a dropout rate of 20%, we aimed to recruit 32 participants.

Outcome measures

Primary outcomes were acceptability and feasibility of delivery of the intervention. Acceptability was assessed using qualitative and quantitative evaluation scores. After each workshop was completed, young people and parents were asked to indicate on a scale, from 1 to 10, how likely they would recommend the programme to other young people and families living with diabetes. Feasibility was measured by collecting data on a) the uptake of the programme, final attendance, and drop-out rate, as well as b) potential barriers to participation.

In addition to the feasibility and acceptability data, participants' mean HbA_{1c} over a period of 12 months (median 12; range 6-12) before the pilot study was used as baseline HbA_{1c}. The first available HbA_{1c} provided 2 – 6 months after the intervention group was completed was used as the follow up HbA_{1c}.

One month after the workshop, families were contacted and invited to complete follow up questionnaires. They were asked how useful they had found the day, how much they enjoyed the activities, and how comfortable they were speaking about diabetes since

participation. They were also asked if they had changed anything in their diabetes management and what benefits they perceived from participating in the program. Lastly, families were given the opportunity to provide feedback for the intervention content, design and delivery. All interviews were transcribed and analysed using qualitative content analysis [14]. All feedback and evaluations were carefully reviewed in order to develop a comprehensive coding system, and codes with similar content were grouped into mutually exclusive themes. R.A.C. and D.C. read and analysed the transcripts separately and then compared the results. The codes and themes were developed and refined by discussions among the authors until consensus was reached.

Number of hypoglycaemic events. Parents were asked how many times their child has experienced an episode of hypoglycaemia in the past month.

Hypoglycaemia Fear survey (HFS). The Hypoglycaemia Fear Survey (HFS)-II was developed to measure behaviours (10-item behaviour subscale) and anxiety (15-item worry subscale) related to hypoglycaemia in diabetes [15,16]. The HFS behaviour subscale records inappropriate behaviour related to fear (maintenance of high blood glucose) as well as appropriate behaviours involving avoidance of hypoglycaemic risks by other behaviours. Each item is rated on a five-point Likert scale ranging from 1 (never) to 5 (always). HFS subscale scores are obtained by summing the items for the behaviour and worry subscales separately, and the HFS total score is obtained by summing both subscale scores. Fear of hypoglycaemia is classified as high if participants scored 'often' or 'all the time' on at least one of the items in the worry scale [17].

Additional questionnaires. Three questionnaires were given to families and young people before and after the groups to see if they would be acceptable and could be easily completed. The three measures used were the diabetes module from the Paediatric Quality of Life Inventory (PedsQL 3.0), The Diabetes Family Responsibility Questionnaire [18], and the Self-Care Inventory [19].

Results

Feasibility

Recruitment. Between 28 July 2014 and 9 December 2014, 89 eligible families (44% females; mean age 12.4 years, range 8-16) received study information either prior to attending or during their clinic appointment. They were then approached to take part during clinic or were called on the telephone. Both mothers and fathers were invited to participate in sessions along with their children.

Uptake, attendance, and drop-out rate. Thirty-four (33%) of the 89 families contacted consented to participate (41% female; mean age 11.8 years, range 8-16 years), and were contacted to arrange a convenient date to attend a group. The groups were based on the young person's age (separated into 8-10 year olds, 11-12 year olds, and 13-16 year olds). Four (or five) families were assigned to each group. Single and mixed gender groups were available. Some families requested groups run in the school holidays. This was arranged where possible. All participants were rung the week before the group to remind them of the arrangements. The median number of times families were contacted to recruit them into the study was 4 (range 1 – 8). Families took between 0 to 63 days before agreeing to take part in the study.

One participant withdrew from the study after giving consent with an additional 11 cancelling the week before or on the morning of the group. The final 22 families participated in seven groups (2 – 4 families per group) delivered by 2 qualified clinical psychologists, an assistant psychologist and a diabetes clinical nurse specialist. One group arranged in the half term holiday was cancelled due to insufficient participants for that session.

Barriers to participation. The main reason given for declining to take part was being unwilling to miss school ($N=35$). Other reasons included being busy and not having time ($N=10$), general disinterest in the study ($N=7$), and living too far away ($N=2$) or transportation issues ($N=1$).

Baseline data collection. A median of 3 (range 1-15) attempts were made to contact people in order to collect baseline data. Baseline data were collected a median of 19.5 days (range 1-115 days) before the group began.

Follow up data. Follow up data were collected in clinic (3 young people, 6 parents), over the phone (14 young people, 9 parents) or via post/email (1 young person, 4 parents). A median of 5.5 (range 1-20) attempts were made to contact people in order to complete the follow up data. It took a median of 45 days (range 22-109) to collect follow up data. One family was unwilling to complete the follow up questionnaires and three families could not be contacted. **Table 2** describes the baseline demographics for people approached, consented, and finally participated.

Acceptability

Quantitative ratings indicated that parents and young people found the day useful and enjoyable, and would recommend it to other families (**Table 3**). Six themes emerged from the content analysis, which are illustrated by quotes from participants. Quotes from young people are identified by gender and age.

- **General enjoyment of the day:**

Participants were unanimously enthusiastic and positive about the workshop.

“I enjoyed the day because we got to explain how we feel and share what we are going through.” (Girl, 9)

“The day has boosted my child’s confidence. She was very apprehensive about attending but was made to feel relaxed and valued during the day. She was able to talk in front of new people and share her knowledge which was a huge achievement for her.” (Parent)

“My son used to have a negative attitude towards hospitals, but this was much more fun and engaging.” (Parent)

- **Parents listening to their children:**

Parents enjoyed listening to their children talk about their diabetes knowledge.

“It was good to see that she can manage it, and understands what affects her blood sugar and see her confidence grow from sharing her knowledge with others and feeling comfortable with talking to others.” (Parent)

“It was nice that he realized he is very knowledgeable. It also made me see how wonderful and amazing he is.” (Parent)

“I will allow her more freedom and not be the one making all the decisions, because she clearly knows what is going on and what she needs to do when she’s high or low.” (Parent)

- **Comfort with sharing and speaking about diabetes:**

Both young people and parents liked sharing ideas and meeting others with diabetes. Young people also indicated that they felt more comfortable speaking about diabetes after participation as opposed to before

“It was amazing to realize that others felt the way I did.” (Girl, 11)

“It was interesting to see how other people are affected differently by low or high blood sugar.” (Boy, 13)

“It’s good to know that others are going through with the same situation, it makes you feel connected. Otherwise you think you’re the only one. You don’t get many opportunities like this.” (Parent)

- **Recognising personal strengths:**

Parents and young people identified how working in the group had helped them see they were doing well.

“I know more about diabetes than I think and know how to look after myself.” (Boy, 15)

“I realized that we’re all coping quite well, even when we think we’re not, and our worries are all quite similar.” (Parent)

“I realized that I deal quite well with pressure and we’re not falling apart—I can pat myself on the back for that.” (Parent)

- **Learning about diabetes:**

Even though many participants had extensive education on diabetes, they still found that the day enabled them to learn more about diabetes.

“I learned what HbA_{1c} means and stands for.” (Girl, 9)

“The insulin game showed me what things affected blood glucose, and how one thing can make it go either way.” (Boy, 13)

“I’ve learned more about diabetes today than I did in three years!” (Parent)

- **Improving self-management**

“I will be more aware of what happens when I’m high or low, and pay more attention to what my body is telling me.” (Boy, 14)

“My son managed to do a cannula change with confidence—this has proved challenging in the past so it is a huge step forward.” (Parent)

In the young people’s session a leaflet was developed called ‘What you need to know about T1 Diabetes’. This is available on the UCLH diabetes website [20].

Quantitative results

Mean HbA_{1c} was 66±12 mmol/mol (8.2±1.1%) before, and 65±13 mmol/mol (8.1±1.2%) after the intervention. The median number of hypoglycaemic episodes in the month preceding completion of baseline assessment was 9.0 (interquartile range 2.3-9.0), and in the month preceding collection of follow up data (which was at least a month after the group) was 4.0 (interquartile range 2.0-9.0). **Table 4** shows the number of children, young people, and

parents identified as having high fear of hypoglycaemia. It also shows the HFS “behaviour” and “worry” scores at baseline and follow up for young people and parents who had high fear of hypoglycaemia at baseline. As a feasibility study it was not powered to detect pre-post differences, therefore no statistical tests have been completed. As the study was primarily designed to assess the general acceptability and feasibility of the intervention, the data from all questionnaires are not given.

Discussion

By working with young people and their families, we developed an acceptable programme that is age-appropriate and addresses the self-identified needs of children and young people with T1DM and their parents in relation to managing hypoglycaemia and hyperglycaemia. All of the focus group participants were clear that it was essential to include a number of aspects of glucose management. This showed that it was not practical or feasible to offer families an intervention focusing only on fear of hypoglycaemia. Young people and parents also helped identify topics of interest that can potentially improve blood glucose control. The content was delivered using psychological approaches that were designed to increase young people’s confidence in self-management and parental confidence in their children’s ability to self-manage. In addition, young people and families preferred for the intervention to be delivered as a one-day programme.

Families were happy to complete the questionnaires that were used in the study; however, the small sample size meant that statistical comparison of the baseline and follow up data is not possible. It was possible to deliver the groups, although recruitment was a challenge and would not have been feasible in a normal clinical context. Whilst not statistically tested, parents appear to have higher fear of hypoglycaemia than children with no apparent change following the intervention. Although formal statistical analysis was not undertaken because of the sample size, there was a small reduction in the number of “hypos” reported by the families without apparently compromising HbA_{1c} levels. Fewer “hypos” may

mediate the relationship between better blood glucose management and lower fear of hypoglycaemia in the long-term [21, 22].

Families also reported a number of positive changes in relation to the day, such as being able to listen to and understand each other more, feeling more comfortable speaking about diabetes, learning more about diabetes, recognizing personal strengths, and improving self-management. For example, young people appreciated being listened to and felt their knowledge was valued and respected, and commented on how the activities helped them pay more attention to their bodies and how to recognize symptoms of hypo- or hyperglycaemia.

In clinics, families repeatedly request additional support, yet we had to call up to eight times in order to discuss the project with some families and the time that it took to decide to take part ranged between 0-63 days (median 8.5 days). The amount of time this would take a member of the clinical team to complete would impact significantly on the ability of most services offering the programme. Despite over 90% of parents scoring high fear of hypoglycaemia on the HFS scales, only 33% initially agreed to participate with an additional third of these families dropping out at the last minute bringing the final recruitment rate to 25%. Last minute cancellation and drop-out has an impact on clinical delivery as it is much harder to run a group if only 1 or 2 participants turn up on the day [23]. This is a common paradox for clinical teams who are asked for support by families; finding the right kind of support clearly needs to be individualised.

Families with children in year 7 or above were unwilling to miss school to attend the groups. Groups were offered in the holidays for young people in year 9/10; however these had to be cancelled due to other commitments suggesting the intervention did not appeal to older age groups. Future groups could test out weekend sessions to better accommodate young people's and parent's schedules.

We found practical difficulties collecting data with significant variation in the time between recruitment and collection of baseline data and when groups began. There were also practical difficulties collecting follow up data a month after the group finished as planned. This would need to be carefully thought about in collection of outcomes for a clinical service. Collection of timely outcome data for the study was only possible with a dedicated research assistant and still only achieved 80% follow up.

The study showed that it was possible to design an intervention that was evaluated positively by 25% of eligible families and that all of the families, children, and young people found the groups enjoyable and would recommend to other families. The qualitative feedback suggests that the group had an impact on how parents perceived their children's ability to manage their diabetes and on young people's ability to communicate with others about diabetes. The programme offered families the chance to learn diabetes-related information from each other, and to reflect on and acknowledge each other's strengths, experiences, and abilities which is a very different approach to current standard education programmes. This had an impact on parent-child relationships and communication, as well as on how they feel about diabetes and how to manage it in the future, which was reflected in the potential reduction in hypoglycaemic episodes without compromising overall metabolic control. However, current acceptability and perceived benefits of the programme is limited to a small sample of participants.

In summary, we developed an intervention to help children, young people, and their parents/carers manage blood glucose levels and general issues of living with T1DM. Involving children and families in the development process helped ensure acceptability of the final programme for those that chose to participate. The study identified significant feasibility issues regarding recruitment and organization of the groups due to participant withdrawals. There were also practical difficulties with collecting baseline and follow up data, such as the number of attempts needed to contact families and the expected drop-out rate.

References

- [1] Wild D, von Maltzahn R, Brohan E, Christensen T, Clauson P, Gonder-Frederick L. A critical review of the literature on fear of hypoglycemia in diabetes: Implications for diabetes management and patient education. *Patient Educ Couns* 2007;68:10–5.
- [2] Brouhard BH. Hypoglycemia. In: Travis LB, Brouhard BH, Schreiner BJ, editors. *Diabetes mellitus in children and adolescents*. Philadelphia: W.B. Saunders; 1987. pp. 169–78.
- [3] Barnard K, Thomas S, Royle P, Noyes K, Waugh N. Fear of hypoglycaemia in parents of young children with type 1 diabetes: a systematic review. *BMC Pediatr* 2010;10:50.
- [4] Delamater AM. Psychological care of children and adolescents with diabetes. *Pediatr Diabetes* 2009;10:175-184
- [5] Hampson SE, Skinner TC, Hart J, Storey L, Gage H, Foxcroft D, et al. Effects of educational and psychosocial interventions for adolescents with diabetes mellitus: a systematic review. *Health Technol Assess* 2001;5:1–79.
- [6] Christie D, Strange V, Allen E, Oliver S, Wong I, Smith F, et al. Maximising engagement, motivation and long term change in a Structured Intensive Education Programme in Diabetes for children, young people and their families: Child and Adolescent Structured Competencies Approach to Diabetes Education (CASCADE). *BMC Pediatr* 2009;9:57.
- [7] Gregory J, Robling M, Bennert K, Channon S, Cohen D, Crowne E, et al. Development and evaluation by a cluster randomised trial of a psychosocial intervention in children and teenagers experiencing diabetes: the DEPICTED study. *Health Technol Assess* 2011;15:1–202.
- [8] Patton SR, Dolan LM, Henry R, Powers SW. Fear of hypoglycemia in parents of

- young children with type 1 diabetes mellitus. *J Clin Psychol Med Settings* 2008;15:252–9.
- [9] Sawtell M, Jamieson L, Wiggins M, Smith F, Ingold A, Hargreaves K, et al. Implementing a structured education program for children with diabetes: lessons learnt from an integrated process evaluation. *BMJ Open Diabetes Res Care* 2015;3(1): e000065.
- [10] Vygotsky LS. *Mind in society: The development of higher psychological processes*. Cambridge, MA: Harvard University Press; 1978.
- [11] Albarracín D, Gillette JC, Earl AN, Glasman LR, Durantini MR, Ho M-H. A test of major assumptions about behavior change: a comprehensive look at the effects of passive and active HIV-prevention interventions since the beginning of the epidemic. *Psychol Bull* 2005;131:856–97.
- [12] Christie D, Channon S. The potential for motivational interviewing to improve outcomes in the management of diabetes and obesity in paediatric and adult populations: a clinical review. *Diabetes Obes Metab* 2014;16:381–7.
- [13] George E, Iveson C, Ratner H. *Problem to solution : brief therapy with individuals and families*. London: BT Press; 1999.
- [14] Graneheim UH, Lundman, B. Qualitative content analysis in nursing research: concepts, procedures and measures to achieve trustworthiness. *Nurse Educ Today* 2004;24:105-12.
- [15] Gonder-Frederick L, Nyer M, Shepard JA, Vajda K, Clarke W. Assessing fear of hypoglycemia in children with Type 1 diabetes and their parents. *Diabetes Manag (Lond)* 2011;1:627–39.
- [16] Gonder-Frederick LA, Vajda KA, Schmidt KM, Cox DJ, Devries JH, Erol O, et al.

- Examining the Behaviour subscale of the Hypoglycaemia Fear Survey: An international study. *Diabet Med* 2013;30:603–9.
- [17] Hajós TRS, Polonsky WH, Pouwer F, Gonder-Frederick L, Snoek FJ. Toward defining a cutoff score for elevated fear of hypoglycemia on the hypoglycemia fear survey worry subscale in patients with type 2 diabetes. *Diabetes Care* 2014;37:102–8.
- [18] Anderson BJ, Auslander WF, Jung KC, Miller JP, Santiago J V. Assessing family sharing of diabetes responsibilities. *J Pediatr Psychol* 1990;15:477–92.
- [19] La Greca AM. *Brief Manual of the Self Care Inventory*. Miami, FL: 1992.
- [20] University College London Hospitals. What you need to know about Type 1 diabetes, 2015. Available from: [https://www.uclh.nhs.uk/OurServices/ServiceA-Z/CYPS/PDIAB/Documents/What young people would like everyone to know about Type 1 Diabetes.pdf](https://www.uclh.nhs.uk/OurServices/ServiceA-Z/CYPS/PDIAB/Documents/What%20young%20people%20would%20like%20everyone%20to%20know%20about%20Type%201%20Diabetes.pdf) (accessed 1 June 2016).
- [21] Gonder-Frederick LA, Fisher CD, Ritterband LM, Cox DJ, Hou L, DasGupta AA, et al. Predictors of fear of hypoglycemia in adolescents with type 1 diabetes and their parents. *Pediatr Diabetes* 2006;7:215-22.
- [22] Leiter LA, Yale JF, Chiasson JL, Harris S, Kleinstiver P, Sauriol L. Assessment of the impact of fear of hypoglycemic episodes on glycemic and hypoglycemia management. *Can J Diabetes* 2005;29:186-192.
- [23] Christie D, Thompson R, Sawtell M, Allen E, Cairns J, Smith F, et al. Structured, intensive education maximising engagement, motivation and long-term change for children and young people with diabetes: A cluster randomised controlled trial with integral process and economic evaluation - The CASCADE study. *Health Technol Assess (Rockv)* 2014;18:1–202.

Tables

Table 1 A summary of the different activities included in the workshop.

Time (mins)	Activity	
15	'Like' Boards	Ice breaker with flip charts for parents and children in two groups facilitated by staff discussing favourite foods, music, hobbies and activities
10	Introductions	In a large group each person says one true thing and one not true thing about themselves and kids have to guess which is the true thing
15	Questions you want answered	Parents and children and young people in separate groups with facilitator thinking about if the day went well what questions they would want answered. Questions are read out and placed on a flip chart.
25	Blood Glucose and Insulin	A game to show how insulin works as a key to allow glucose to enter cells and what happens if insulin not present. Young people play the role of the cell, the door, the insulin and blood glucose. Worksheet given out to take home
10	Break	
30	Factors influencing blood glucose levels	Parents and kids in different groups with a facilitator. Each group given a number of cards describing different factors that affect blood glucose levels and have to decide if they make blood glucose go up down or both. Facilitator goes through the different cards encouraging young people to give reasons for their choices. Worksheet with correct answers given out to take home
10	HbA _{1c} – DCCT trial	Workshop leader talks through what HbA _{1c} stands for (using developmentally appropriate language) and shows the DCCT complications chart to illustrate why HbA _{1c} is given such importance by parents and clinic staff.
40	Hypoglycaemia and Hyperglycaemia	Young people are interviewed as a group by the workshop leader about “hypo” and “hyper” symptoms, what the effects are at home and in school and what they need to do to manage both situations.
10	Parents reflections	Parents are interviewed and asked what struck them listening to the young people, what they have learned and what they might do differently
	Lunch	

60	Parents / 8-12 age group	<p>Young people meet on their own with 2 workshop leaders. The specific activity is designed by the psychologist during the lunch break and depends on the developmental and cognitive level of the group. The aim is to invite kids to identify their strengths abilities and resources and think about ways to answer back questions other people have about diabetes. A variety of media are used during this session</p> <p>Parents are offered a group session facilitated by a workshop leader (qualified psychologist). Parents are invited to use the session to discuss whatever topic they would like to so each session is always different. They are also reminded of the questions they raised at the beginning of the day to see if any of these have been answered</p>
15	Bring back for feedback	Parents return to hear about the output the young people have designed
10	Break	
30	Question Time	Based on the BBC programme format young people make up a panel and answer the questions that were identified at the beginning of the day. Parents act as the audience
30-40	Blueprint for success - Going to do differently	<p>Young people are interviewed about what they enjoyed, what they learned what they will do differently as a result of attending the workshop and what they have appreciated about each other. The answers are written on certificates called a Blueprint for success.</p> <p>Parents are then invited to reflect on what they heard their children talk about and asked what they were struck by and what they will be doing differently and asked to contribute their appreciations of the young people</p>
5	Evaluation Post it notes	Participants are invited to say in a scale of 1 to 10 whether they would recommend the day to other families with diabetes.

Table 2 Demographic characteristics data and HbA_{1c} for the 89 approached, the 33/34 that consented and completed the baseline questionnaire, and the 22 that participated.

	Approached (N=89)	Completed baseline questionnaire (N= 33)	Actual participants (N=22)
Female, <i>N</i> (%)	39 (44%)	19 (48%)	8 (36%)
Age (years), mean (SD)	12.4 (2.5)	11.8 (2.7)	11.2 (2.8)
Ethnicity			
White, <i>N</i> (%)	72 (81%)	33 (83%)	17 (77%)
Asian/Asian British, <i>N</i> (%)	8 (9%)	4 (10%)	3 (14%)
Black, <i>N</i> (%)	6 (7%)	2 (5%)	1 (5%)
Other Ethnicity, <i>N</i> (%)	3 (3%)	1 (3%)	1 (5%)
Time since diagnosis (years), mean (SD)	6.3 (3.4)	6.1 (3.4)	6.2 (3.2)
Time since enrolled at clinic (years), mean (SD)	3.6 (2.8)	3.6 (2.6)	3.91 (3.0)
HbA _{1c} , mean (SD) *			
mmol/mol	69 (11)	64 (8)	66 (12)
%	8.5 (1.4)	8.0 (1.0)	8.2 (1.1)
Number of hypoglycaemic episodes in the last month Median (IQR)	Not available	9.0 (7.0)	9.0 (6.8)
Number of people with High fear of hypoglycaemia (%)			
Young people	Not available	17/33 (52)	15/22 (61)
Parents	Not available	31/33 (94)	20/22 (91)

* The median number of recorded HbA_{1c} values for each participant was 3 (range 1 -5)

Table 3 Quantitative evaluation.

	Child Mean (Range) <i>N</i> =21	Parent Mean (Range) <i>N</i> =21
Recommendation of the day		
On the day*	9.0 (6.5-10)	9.6 (7.5-10)
Follow up (22-109 days later)	9.1 (8-10)	9.4 (5-10)
Usefulness of the day	8.6 (5-10)	8.9 (7-10)
Enjoyment of the day	8.9 (3-10)	9.1 (5-10)
Comfort speaking about diabetes		
Before participation	6.0 (1-10)	8.5 (1-10)
After participation	7.4 (3-10)	8.8 (1-10)

**N*=22 for evaluation on the day

Table 4 Baseline and follow up data on the Hypoglycaemia Fear Survey for YP and parents identified as having high fear of hypoglycaemia at baseline. Higher scores indicate higher fear of hypoglycaemia.

	YP Baseline (N=15) Mean (SD)	YP Follow up (N=9) Mean (SD)	Parent Baseline (N= 20) Mean (SD)	Parent Follow up (N=17) Mean (SD)
Behaviour score I (maintenance of high blood glucose)	39.7 (20.8)	29.5 (18.1)	42.9 (22.2)	43.1 (12.3)
Behaviour score II (avoidance of hypoglycaemic risks)	64.3 (17.9)	61.5 (32.1)	68.5 (14.1)	78.5 (17.1)
Worry score	39.7 (18.9)	32.1 (20.2)	53.6 (20.0)	49.1 (20.7)
High fear of hypoglycaemia (%)	15/22 (68)	9/18 (50)	20/22 (91)	17/19 (89)