

WICKED: The development and evaluation of a psycho-education programme for young people with type 1 diabetes

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Structured education courses are available for adults with diabetes and are associated with improved glycaemic control and quality of life. However, they may not be appropriate for young people who often have sub-optimal glycaemic control. In this study, seven young people aged 16–21 were surveyed about a Dose Adjustment for Normal Eating (DAFNE) course and reported that it did not reflect their needs and they required more information on social issues. An age-appropriate self-management programme was then developed, called Working with Insulin, Carbs, Ketones and Exercise to Manage Diabetes (WICKED) and trialled with nine young people. WICKED was well received by the young people who enjoyed meeting and learning from their peers. This approach is worthy of further development and evaluation.

Validated structured education courses such as DAFNE (Dose Adjustment for Normal Eating; DAFNE Study Group, 2002) are available for adults with diabetes and have been associated with improved glycaemic control and quality of life (Speight et al, 2010). However, DAFNE may not be appropriate for young people as they make the transition to take greater responsibility for self-care. As the care of diabetes management transitions from parent to child, young people often find themselves responsible for self-management despite having received little training to do so. It is important that young people are given appropriate education and support so that they can establish a positive approach to managing diabetes early in life. Structured education courses have been developed for children and young people, such as KICK-OFF (Kids In Control of Food). Based on DAFNE principles, KICK-OFF is currently being evaluated in a national randomised controlled trial. Unfortunately, however, this course has only been designed for 11–16 year olds. Young people with type 1 diabetes aged 16–24 often have poor glycaemic control, with 33%

having an HbA_{1c} above 86 mmol/mol (10%; NHS Information Centre, 2011). Changing biological, psychological and social factors will often contribute to deteriorating diabetes control (McNamara et al, 2010). It is important that young people are given appropriate education in self-management so that they can establish a good approach to managing diabetes early in life.

This article describes the development of a complex intervention to improve the delivery of care for young people with type 1 diabetes (Eiser et al, 2013). In Phase 1, young people's views of a standard DAFNE course are surveyed. Phase 2 involved using their comments to create an age-appropriate course that was specifically designed for young people with type 1 diabetes. This course, "Working with Insulin, Carbs, Ketones and Exercise to manage Diabetes" (WICKED), was then put into practice in a small pilot study to determine acceptability.

Phase 1: Views about DAFNE Method

Seven young people aged 16–21 years attended a

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Article points

1. The authors developed and piloted a diabetes education programme, WICKED, tailored to the requirements of 16–21 year olds.
3. WICKED includes differentiated learning objectives, assessment for learning, psychosocial elements, practical sessions and structured follow up.
4. Participants on the pilot gave positive feedback, particularly about the pictorial method of blood-glucose review and the confidential discussion of psychosocial issues.

Key words

- Education programme
- Psychosocial
- Type 1 diabetes
- Young people

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one-week DAFNE course, and were offered follow-up at six weeks. The course met all the learning outcomes of DAFNE, but some modifications had been made to make it more relevant for younger people. These changes included the use of bolus advisors, having a clinical psychologist and a person with diabetes as guest speakers, social activities on the last day and an earlier finish on day three. The course was delivered by two DSNs and a dietitian. Health psychologists observed the course and the follow-up meeting. They also led a focus group with the participants at the end of the course and interviewed facilitators both before and after the course.

Results

Observations and data from interviews and focus groups allowed triangulation of findings and verification that the feedback was representative of the course experience.

Views of young people

Young people responded positively to the DAFNE course. They enjoyed meeting others with diabetes and they felt it was important to meet others in the same situation; one young person commented:

“I didn’t know anyone before who had diabetes, who wasn’t, like, over 70, or something.”

They enjoyed the practical sessions about carbohydrate counting and alcohol, and interactive sessions; reporting that they were happy “not to be talked at”. They liked the opportunity to use a bolus calculator and felt this would help them with their diabetes management.

Participants thought the week-long course was better than separate days and welcomed the six-week follow up. Though young people were positive about the course overall, some organisational and content issues were raised. They felt that some sessions, such as the history of insulin regimens and more detailed carbohydrate counting methods, such as weighing foods and calculating recipes, were not relevant. They also felt they knew about healthy eating already. Other social issues, such as alcohol, driving and recreational drugs needed to be explained in more detail. They found some sessions too intense and lengthy, wanted more breaks and a shorter day. The dose adjustment sessions, which is an integral part of DAFNE, were seen to be useful but they felt

they became boring. They described being tired after lunch and felt they should do something practical at this time.

Facilitator views

Facilitators were happy that the participants “gelled well as a group”, attended for the week and that they had all adopted the DAFNE-taught behaviours by the end of the week. The DAFNE workbook and carbohydrate portion list were only used when directly advocated by the facilitators. This suggests that the workbook and carbohydrate portion list were impractical, not engaging or not useful for this age group.

Facilitators echoed participants’ concerns about the length of sessions, noting a lack of concentration after 45 minutes and they felt that some of the curriculum did not feel appropriate for the age group.

Facilitators also felt dose adjustment sessions were potentially problematic as participants engaged when discussing personal blood glucose profiles but found it difficult to remain focused when discussing other participants. They observed that it was a challenge to manage the dynamics of the group at times and keep them continually engaged. They found that the numerous learning outcomes made it difficult to explore other topics that interested the group. They were concerned about young people maintaining the self-management behaviours after the course had ended.

Six-week follow up

Participants reported that they “hit the wall” three weeks after attending the DAFNE course and were no longer able to maintain the changes to self-management. They requested earlier follow-up to help consolidate these changes into day-to-day diabetes care. Despite enthusiasm on the course, none of the participants were using the bolus advisor by week six. The facilitators were concerned that the young people may not be able to calculate insulin ratios and correction doses without using this technology.

Phase 2: Development of WICKED

After phase 1, a consultation meeting was held with key representatives of the DAFNE and KICK-OFF programmes, educationalists and health psychologists from the University of Sheffield, and members of the

paediatric and adult diabetes multidisciplinary teams. This resulted in the development of a structured education course specific to the requirements of young people with diabetes. Using DAFNE as a baseline, facilitators worked collaboratively with educationalists to adapt the content, organisation and delivery to reflect the young people’s evaluations of DAFNE. Facilitators also received training to support the development and delivery of the new course, WICKED. The DAFNE-trained nurses and dietitian received additional training in psychological interventions, adolescent health and teaching skills for secondary-school age children from university PGCE (post-graduate certificate in education) tutors.

WICKED is based on principles derived from constructivist learning theory (Matthews, 1997). It embraces a patient-centred approach within a therapeutic peer-supported environment, building on prior knowledge and experiences to influence new knowledge construction. The approach aims to build self-efficacy through acknowledging the previous experiences young people have had, such as experimenting with drinking alcohol, and aims to develop new learning based on these experiences.

The key sessions, shown in *Table 1*, were similar to DAFNE sessions but subjects that have been identified as particularly important to young people have been added and can be explored in more detail. Basic principles of carbohydrate counting were introduced in the session called “Think like a pancreas” but the majority of carbohydrate counting education was delivered practically during the provision of familiar meals and snacks.

A session that specifically focused on the psychosocial issues of living with diabetes was introduced. This involved reflection and problem solving for challenging scenarios via a group discussion, led by the facilitators. Participants were given the opportunity throughout the week to provide personal experiences to be discussed anonymously in this session. Topics covered included insulin omission, disordered eating and the effect of diabetes on relationships.

“Results like a pancreas” involved participants creating WICKED graphs to display blood glucose levels with a stepped progression, annotated with contributory factors (*Figure 1*). Using the graph not only helped the young people visualise any patterns in blood glucose profiles more easily, but also to

Table 1. Timetable for the 5-day WICKED pilot course.

Time	Monday In the know	Tuesday HIs and lows	Wednesday Back on track	Thursday The road to success	Friday Go for it!
9.30	Introductions	Results like a pancreas	Results like a pancreas	Results like a pancreas	Results like a pancreas
10.15	Break time				
10.30	Think like a pancreas	Corrections and snacks	Sick day rules; short-term health	Alcohol and recreational drugs	Eating out
11.15	Break time				
11.30	Act like a pancreas	Hypos	Annual review: long-term health	Social issues	Evaluation
12.15	Lunch (Carbs and cal)	Lunch (Food labels)	Lunch (Weighing)	Lunch (Internet)	Lunch (Eating out)
13.00	Results like a pancreas	Exercise	Results like a pancreas	Living with diabetes	
13.45	Break time		Finish	Break time	Bowling
14.00	Review of the day, 1-to-1 time	Results like a pancreas, 1-to-1 time if required		Results like a pancreas, 1-to-1 time if required	
15.00	Finish	Finish		Finish	Finish

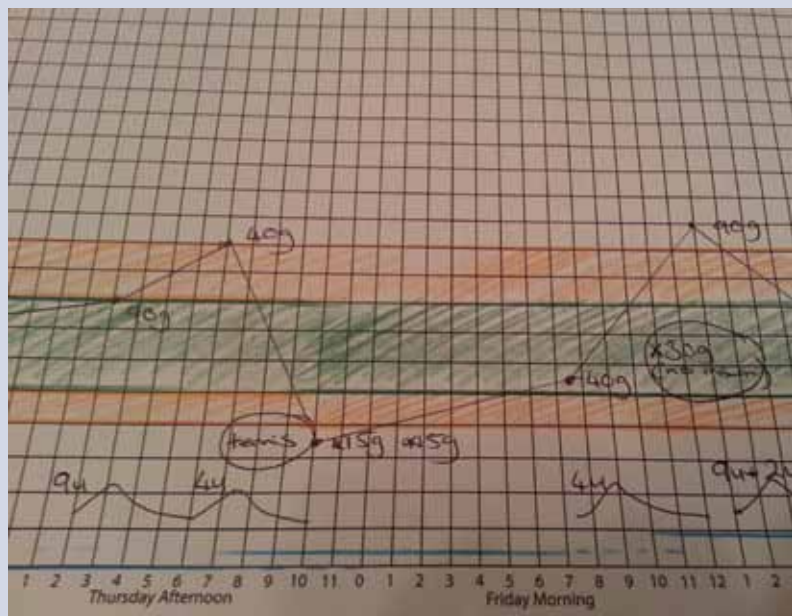


Figure 1. A participant’s colourful WICKED graph showing blood glucose levels

Page points

1. The participants commented on the benefits of meeting peers on the course and learning directly from other people's experience.
2. The WICKED blood glucose level graphs were received well by the participants.
3. All participants set personal goals to be worked on after the course.

see how close they were to target blood glucose levels. Participants set their own target ranges and formulated action plans to improve blood glucose profiles in a paired "Diabetes detective" activity.

Changes to organisation and delivery

The WICKED pilot course introduced significant changes to the delivery of sessions based on the phase 1 evaluations. Changes were made to teaching methods and more practical activities were included. Consideration was also given to optimum session length, position within the day and the structure of the week-long course to support maximum engagement and to ensure there were opportunities for one-to-one support.

Each session was based on an assessment for learning. This included initial diagnostic activities to ascertain prior knowledge and experience that were used to tailor learning outcomes for each participant. Sessions were based on a variety of practical activities, which were incorporated to accommodate a mixture of learning styles using both individual and group work.

The information included in each session was tailored to this age group and chosen to allow for a shorter day. The essential educational points for each session were prioritised to allow flexibility for the requirements of the group. Differentiated learning objectives were stratified to be achieved by "all", "most" or "some".

Follow-up was scheduled at weeks 3, 6, 9 and 12, with aims to review personal goals and integrate these into routine clinics with a named key worker.

Phase 3: Acceptability of WICKED to young people

Nine young people aged 16–21 years attended the one-week course and took part in an evaluation at the end of the week led by the facilitators. They were asked to provide written details about: something I have learnt; something I have enjoyed; something that was not useful; I would like more information on...; following this week I am going to... and any other comments. Content analysis was used to summarise their views. All evaluations were completed anonymously.

Results

Five participants commented on the benefit

of meeting peers with diabetes and learning directly from other people's experiences. They specifically learnt something about management of hypoglycaemia ($n=4$), exercise ($n=3$), alcohol ($n=3$) and illness ($n=2$). The WICKED graphs were received well and comments included:

"The graphs also encouraged me to test my blood sugars more regularly so I could easily see where I needed to change my background insulin."

One person felt some sessions were too long and three identified different sessions (alcohol, carbohydrate counting using food labels and hypoglycaemia management) that they did not find useful because they already knew about these subjects. All additional comments made were positive:

"The whole week has been a brilliant experience and I am so grateful for it! Cheers!"

More depth regarding social issues, specifically eating out ($n=2$), exercise ($n=2$) and longer term health ($n=1$) was requested with accompanying written information ($n=3$). Comments were also received about specific sessions:

- Living with diabetes: *"Great to talk about issues we feel are necessary to us all personally but anonymously."*

- Social issues: *"The social issues session was really helpful. It covered the issues concerning us which made it interesting"* and *"Great talking about social issues, subjects that I never remember to mention in clinic."*

- Long-term health: *"Great to talk about long-term problems. Really gave me the incentive to change the way I look after myself."*

All participants set personal practical diabetes management goals at the end of the week and these were reviewed at follow up sessions every three weeks for three months.

Discussion

Developing a skills training course to engage young people has not been without its challenges and the following issues arose during implementation that would need consideration when running the course again:

- Recruitment was difficult, as people had to commit to attending a week-long course; however, among those who agreed to participate, all attended well and completed the course.
- The majority of the participants were reliant on public transport and travel costs were an issue for some. Transport was organised in exceptional circumstances and bus passes will be provided in future.
- The final afternoon was spent off-site meaning additional transport and safety measures were necessary. Using an alternative venue for the course away from the hospital may have avoided these issues and provided a better environment for the participants.
- WICKED is designed for people using multiple injection therapy or insulin pumps and therefore, the curriculum needs to be sensitive to the requirements of both methods of insulin administration, and the facilitators must have adequate knowledge of both methods.
- Two members of staff were needed for all sessions to provide one-to-one support where this was needed, including at break times.
- Participants were encouraged to set their own target ranges, which may not reflect national guidelines. Evidence supporting national guidelines was discussed during the long-term health session and demonstration WICKED graphs reflected the guidelines.
- All meals and snacks were provided. Snacks were provided, but many were initially eaten without insulin. This was used non-judgementally as a learning experience during work on the WICKED graphs in the “Results like a pancreas” session when the implications of not taking appropriate insulin for snacks was emphasised.
- Follow-up group sessions were negotiated during the WICKED week. However, participants had many additional commitments and it was difficult to find mutually convenient times. Predetermined follow-up dates may be more feasible. The WICKED pilot was held in the August school holidays (as recommended by those in the DAFNE evaluation). Even so, summer jobs and holidays prevented some potential participants from attending.
- Parents of young people with diabetes require additional help to support their child’s

transition to adulthood (Eiser et al, 2013) and a supplementary half-day programme has been developed for parents to provide skills and assistance to help them best support their child.

- Following this pilot work, changes have been made to the WICKED curriculum and a scheme of work has been devised. This is a comprehensive guide incorporating the philosophy, curriculum and other supportive materials. It also includes postcards detailing the key points of each session.

Conclusion

WICKED is currently being evaluated as part of a complex intervention for young people with type 1 diabetes. In addition to its impact on HbA_{1c} levels, the evaluation will include psychosocial measures as well as further explorations of its acceptability. As such, the efficacy of the course remains to be seen, but initial findings about the process of interactive development involving young people suggest that the structured education course will meet the needs of young people with type 1 diabetes both in terms of content and delivery. ■

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