

ASPIRE: A local insulin skills programme for adults with type 1 diabetes

Dee Clark

Article points

1. Research evidence indicates that insulin skills programmes improve the physical and psychosocial health of people with type 1 diabetes.
2. Reflection diaries can provide a rich insight into the personal experiences and perspectives of people with type 1 diabetes during their educational encounters.
3. People with type 1 diabetes place quality of life at the top of their agenda therefore, educational programmes should measure and assess these outcomes.

Key words

- Diabetes education
- Local insulin skills programmes
- Self management
- Quality of life
- Reflection diaries

Dee Clark is a Nurse Consultant (Diabetes Care) at Chesterfield Royal Hospital NHS Foundation Trust, Chesterfield.

In this article retrospective data from 20 participants who attended ASPIRE (A Skills Programme in matching Insulin Requirements to Eating and exercise) were analysed using both quantitative and qualitative methods. The main outcomes measured were glycaemic control (HbA_{1c}) and psychosocial health. The results reveal that clinically significant improvements in both glycaemic control and psychosocial health were achieved and maintained to the 6-month post programme assessment.

Since publication of the first DAFNE (Dose Adjustment for Normal Eating) study (DAFNE Study Group, 2002) various locally adapted models have been reported in the literature as providing an alternative and more cost effective DAFNE-style education course. Although these programmes have not undergone the rigors of randomised controlled trials they report similar outcomes to those identified in the DAFNE study (Everett et al, 2003; Sumner et al, 2003). It has also been recognised by the Department of Health that locally adapted models of diabetes education may well fit their quality criteria (DoH, 2007).

Like its cousins BERTIE (Bournemouth's Education Resources for Training in Insulin and Eating) and DAFNE (see *Box 1*), ASPIRE (A Skills Programme in matching Insulin Requirements to Eating and exercise) was designed to help adults with type 1 diabetes focus on developing new skills for self-management, which includes calculating insulin doses to more closely match dietary and exercise habits (see *Box 2*).

ASPIRE is aimed at adults with type 1

diabetes and is undertaken in groups of six to eight participants. The education programme is conducted at a local community centre where kitchen and exercise facilities are available. See *Figures 1–3* for photographs of ASPIRE in action. Various teaching strategies are employed to engage participants in the educational process, such as: group work, role-play and workshops. Participants also keep food, exercise and reflection diaries and present their blood glucose profiles on an acetate overhead projector sheet on a weekly basis.

There is a strong emphasis throughout ASPIRE on learning about food groups and in particular about carbohydrate counting. The theoretical framework that underpins the course is the Social Learning Theory because it is the most commonly used framework. It describes the way in which people become confident to self-manage their diabetes and develop their ability to make appropriate behaviour changes (Everett, 2007). The theory is consistent with the principal characteristics of adult learning (Powers et al, 2006).

During an ASPIRE session participants are

Box 1. Characteristics of DAFNE and BERTIE.

DAFNE

- A skills-based structured education programme in intensive insulin therapy.
- Delivered by specially trained specialist nurses and dietitians.
- Taught in groups of 6–8 over a consecutive 5-day period on an outpatient basis.
- Teaches the principles of flexible insulin adjustment to match carbohydrate in a free diet on a meal-by-meal basis.
- The only insulin skills programme that has undergone a controlled trial in the UK (Reid, 2003).
- The only structured course for people with type 1 diabetes recognised as meeting government criteria for quality assurance in diabetes education (DoH, 2005; Hill et al, 2006).

BERTIE

- Programme runs for 4 days over 4 consecutive weeks (This programme modification was made in order to meet the needs of the local population and the availability of resources [Everett, 2003]).



Figure 1. Calculating carbohydrate values with use of calculator and carbohydrate counter booklet.



Figure 2. Comparing portion sizes for 50g of potato baked, chipped, mashed and boiled.



Figure 3. Group discussion and experiences of carbohydrate counting.

Box 2. Developing ASPIRE.

ASPIRE

- Development began following completion of an educators training programme in Bournemouth in early 2005. The original development team comprised a Nurse Consultant, Senior Dietitian and Diabetologist.
- Due to resource implications only 3 courses per year have been undertaken however, ASPIRE has now been officially commissioned by the local PCT it is envisaged that programme capacity will double.
- The facilitators are the Nurse Consultant for diabetes and the Senior Dietitian (diabetes care) with involvement from one of two Diabetologists who facilitate the complications section of the programme.
- The course runs for 4 days over 4 consecutive weeks as this has the advantage of providing participants with an opportunity to practice their new skills during the programme, rather than just after it has been completed (Everett et al, 2003).

encouraged to learn from each other by sharing personal experiences of living with diabetes.

Aims

Data have been collected about ASPIRE participants since the programme began in late 2005 and was recently analysed to determine whether or not clinical and psychosocial outcomes improved in the months following the programme.

Methods

For the analysis a purposive sample of participants was selected.

Data collection

Primary data were collected prior to the

educational programme to determine baseline data on clinical and psychosocial parameters. The following measures were used.

- HbA_{1c} measurements at 3, 6 and 12 months. Only one group had completed the 12 month assessment when the evaluation was undertaken, therefore data analysis was undertaken for a 6-month period only.
- Quality of life questionnaire using the Problem Areas in Diabetes (PAID) tool (Polonsky, 2000; Burroughs et al, 2004). When completing the PAID questionnaire, participants rate themselves according to their perceived diabetes related problems. This is achieved by allocating a number to all 20 questions on a 5-point Likert scale ranging from 0 (not a problem) to 4 (serious problem).
- Reflection diaries.

Also recorded were BMI and frequency of self reported episodes of hypoglycaemia, episodes abstracted from hospital admission data and from paramedic records. However, due to time constraints the author was unable to complete analyses on these data.

Data analysis

Quantitative data extracted from clinical observations (HbA_{1c}) and the PAID results were analysed using validated instruments (Polit and Hungler, 1997). Pre- and post-intervention data were analysed in the same participants using t-tests. Microsoft Excel 2000, statistical tables and support from a statistician were used.

First-phase analysis identified that the related t-test was an appropriate statistical test to use for the HbA_{1c} results as the data were as interval levels of measurement and relatively normally distributed. However, the PAID results were not normally distributed. As such, a non-parametric test (Wilcoxon Signed-Ranks Test) was used as an alternative. Although non-parametric tests are considered to be less sensitive, they are widely used in research (Polit and Hungler, 1997; Crookes and Davies, 1998). Content analysis, which is considered to capture the interactions within a group (Polit and Hungler, 1997; Coates, 2004) was used to code themes into categories and to look for patterns, consistencies and inconsistencies in the qualitative data collected from the ASPIRE

participants' evaluation forms and reflection diaries. A theme matrix was used to simplify this process.

Results

Baseline, 3-month and 6-month data were available for 20 participants who completed ASPIRE. More women than men completed the course (12 versus 8, respectively). The mean age was 43 (range: 19–73 years) with mean duration of diabetes being 20 years (range: 1–48 years).

Figure 4 shows HbA_{1c} results. Although other parameters were measured pre- and post-ASPIRE, HbA_{1c} (as a measure of glycaemic control) was selected for analysis due to its importance in terms of clinical outcomes (DCCT Research Group, 1993). Baseline mean HbA_{1c} was 8.35% (SD: 1.14; range: 6.4–10.6%) and at 3 months HbA_{1c} had significantly improved (mean decrease: 0.74%; $P \leq 0.001$). The mean HbA_{1c} at 6 months was significantly lower than at baseline: 7.64% (range: 6.2–9.9%) versus 8.35%, respectively, ($P \leq 0.005$). There was no significant change in

mean HbA_{1c} between the 3- and 6-month follow ups ($P > 0.2$).

There was a remarkable and highly significant improvement in quality of life (represented by PAID scores), which is shown in Figure 5. At pre-intervention, the mean PAID score was 21.8 (range 8–51). At 3 months this had decreased to 11.8 ($P \leq 0.005$) and at 6 months to 7.5 ($P \leq 0.005$).

Participant experiences

Exploration of ASPIRE experiences were analysed by reviewing comments recorded in participants' reflection diaries throughout the course. Content analysis was used to identify the main concepts that emerged from this data (Crookes and Davies, 1998). On analysing the experiences of the participants during their educational intervention four key themes were identified:

- motivation
- self management
- confidence
- empowerment.

The reflections indicated how participants' felt about the ASPIRE course and provided a rich insight into the emotional world of life with diabetes.

Motivation

All participants who undertook ASPIRE alluded to motivation in their reflections and this was clearly an important issue in managing their diabetes. The following comments provide an example of the central importance of motivation.

'I'm enthusiastic about food shopping for the first time since I was told I had diabetes.'

Participant 3, male, age 19 years, diabetes duration 15 years.

'You know, I thought I knew it all before this course but it has been a real eye opener.'

Participant 9, female, age 42, diabetes duration 2 years.

Self management

The challenge of dealing with diabetes on a daily basis was evident in the reflection diaries. The importance of choice, autonomy, being in control and decision-making were all identified as issues in self-managing the condition.

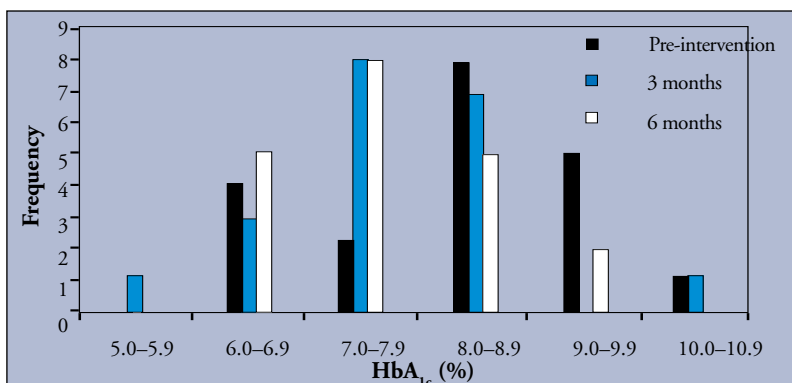


Figure 4. Frequency distribution of HbA_{1c} results.

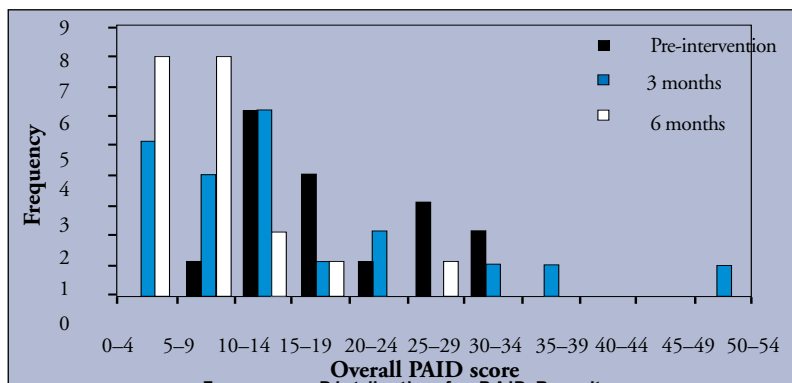


Figure 5. Frequency distribution for PAID scores.

'Until this course I thought I had to do what the doctor told me to even if I didn't agree...[but]...it's my life, my diabetes, my choice.'

Participant 3, male, age 19, diabetes duration 15 years.

'I have learned so much that I didn't know before and I will be able to deal with things much easier...It's not my fault I got diabetes but its down to me to deal with it.'

Participant 11, male, age 31 years, diabetes duration 13 years.

Confidence

The reflections diary completed by participants highlighted the fact that for some individuals a diagnosis of diabetes triggered a sense of bereavement. As a consequence this can lead to fear, anxiety, grief, anger, loss of self esteem and lack of confidence. It was not surprising that the study participants highlighted these issues in their reflection diaries, for example:

'Life was never the same after I was told I had diabetes although it did get better with time...I used to think that if I injected my insulin and there was an air bubble in it, it would kill me.'

Participant 19, female, age 21 years, diabetes duration 10 years.

'Ever since I developed diabetes I've been insecure, I didn't used to be...I used to live in fear of hypos, not anymore.'

Participant 5, male, age 33 years, diabetes duration 4 years.

Empowerment

Within the context of diabetes care, empowerment means an individual with diabetes should be provided with sufficient information, education and skills training to enable them to make informed decisions about their health management. Furthermore, the individual is also responsible for the consequences of any decisions they take. The ASPIRE participant reflections identify a diversity of opinions about this issue, for example:

'I never knew I should change my insulin doses I thought that only the doc could do that...How am I supposed to choose the right foods if I don't know what the right ones are?'

Participant 6, female, age 35 years, diabetes duration 34 years.

'She told me off for using them [needles] too long. I didn't know they go blunt...Everybody assumes you know all about it [diabetes] if you've had it as long as I have but they never had courses like this when I was diagnosed.'

Participant 8, female, age 51 years, diabetes duration 40 years.

'Am I a bad diabetic because I want to do what I want when I want?'

Participant 10, male, age 35 years, diabetes duration 34 years.

Discussion

The data from this retrospective evaluation indicate that undertaking a skills programme designed to help adults with type 1 diabetes to match insulin requirements to insulin does, in the short-term at least, improves the physical and psychosocial health of people with type 1 diabetes. The ASPIRE educational intervention produced an HbA_{1c} improvement comparable with those found in other studies (DAFNE Study Group, 2002; Everett et al, 2003; Plank et al; 2004) and this remained statistically significant at the 6-month follow up. The mean improvement in HbA_{1c} of 0.74% is clinically significant in terms of its potential to reduce the risk of diabetes related complications.

The results of the PAID tool and participants' personal reflections about ASPIRE illustrate the personal gains achieved. In particular, perceived quality of life, as measured by the PAID tool, showed a remarkable reduction in diabetes-related problems after the education programme which remained significant at the end of the current observation period (6 months). The significance of these results cannot be understated, particularly as health-related quality of life is increasingly recognised as the single most important clinical and research outcome (Burroughs et al, 2004; Polonsky, 2005).

It was clear from the personal reflections of ASPIRE participants that they valued an educational programme that placed them at the centre of learning which acknowledged their personal expertise and experiences of living with diabetes. Addressing the physical and

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2. The ASPIRE educational intervention produced a HbA_{1c} improvement comparable with those found in other studies and this remained statistically significant at the 6 month follow up.
3. The mean improvement in HbA_{1c} of 0.74% is clinically significant in terms of its potential to reduce the risk of diabetes related complications.
4. The results of the PAID tool and participants' personal reflections about ASPIRE illustrate the personal gains achieved.
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Page points

1. Intensive insulin management programmes incorporating both behavioural and skills training components appear to be gaining momentum and continue to report positive outcomes.
2. It would appear from the reflections analysed that understanding, knowledge, experiential learning and peer support were contributory factors in helping the ASPIRE participants to find the motivation to contemplate or make the behavioural changes that would improve or enhance their diabetes self-management.
3. There is sufficient evidence to indicate that people who make their own decisions achieve significant reductions in their HbA1c and have improved quality of life.
4. The negotiation of a care plan at diagnosis may be of critical importance in terms of how the individual will cope with the diagnosis in the first instance and develop the appropriate skills and knowledge to be able to manage the condition in the longer term.
5. The importance of people with diabetes and their healthcare professionals working in partnership towards mutually agreed goals is, therefore, essential and more likely to achieve successful outcomes for both sides of the therapeutic alliance.

pyschosocial needs of patients is considered to be a prerequisite if educational interventions are to have positive outcomes (Coates and Boore, 1998; Delamater et al, 2001) and has been identified as something people with type 1 diabetes want from their educational encounters (Hiscock et al, 2001; Richards et al, 2006). Such an approach has also been identified as essential in promoting effective health alliances between people with diabetes and their healthcare professionals (DoH, 2001; DoH, 2006).

Identifying which particular components of an educational process have the greatest positive impact on outcomes remains the elusive 'holy grail' of diabetes education and has been much debated in the literature (Cooper et al, 2002; Day et al, 2003; Avery, 2006). However, intensive insulin management programmes incorporating both behavioural and skills training components appear to be gaining momentum and continue to report positive outcomes (DAFNE Study Group, 2002; Everett et al, 2003; Samann et al, 2005).

The ASPIRE participants in the current study identified several key behavioural themes that appeared to be important factors in their successful journey through the course. They highlighted the importance of learning new skills or building on existing skills related to insulin management, diet and blood glucose monitoring. Additionally, being part of a group may have contributed to the improvements observed in this study. It has previously been identified that group education can improve the quality of life of individuals with diabetes, independent of any other factors (Hiscock et al, 2001; Diabetes UK, 2002; Trento et al, 2004). However, the four key topics identified were motivation, self management, confidence and empowerment.

Motivation

According to the literature, if diabetes educational programmes are to be effective they must firstly identify the patients' priorities (Day, 1995; Hampson et al, 2001). It would appear from the reflections analysed that understanding, knowledge, experiential learning and peer support were contributory factors in helping the ASPIRE participants to find the motivation to contemplate, or make the behavioural changes

that would improve or enhance their diabetes self-management.

Self management

There is sufficient evidence to indicate that people who make their own decisions achieve significant reductions in their HbA_{1c} and have improved quality of life (Hampson et al, 2001; DoH, 2005). The reflections from participants on the course appear to support this.

Confidence

Living with type 1 diabetes can be daunting as nearly all of the day-to-day care has to be undertaken by the person who has the condition. Self-management therefore, is not an option but an essential requirement if the individual is to avoid the short- and long-term complications associated with diabetes.

It would appear from the participants' comments that diabetes can affect people's confidence levels in all the domains of their lives. Therefore, the negotiation of a care plan at diagnosis may be of critical importance in terms of how the individual will cope with the diagnosis in the first instance and develop the appropriate skills and knowledge to be able to manage the condition in the longer term. Furthermore, the importance of encouraging partnerships between people with diabetes and their healthcare professionals was highlighted in the NSF for diabetes (DoH, 2001), which states that by empowering people with diabetes they will be able to gain personal control over the management of their diabetes.

Empowerment

It is interesting that the participants' comments regarding empowerment reflected the central aspects of empowerment. These include the importance of gaining knowledge, skills, and understanding how to manage diabetes effectively. However, participants also recognised that any decision they took might differ from the advice proffered by healthcare professionals. The importance of people with diabetes and their healthcare professionals working in partnership towards mutually agreed goals is, therefore, essential and more likely to achieve successful outcomes for both sides of the

therapeutic alliance.

Data on participants' weight and hypoglycaemic episodes were collected pre- and post- course, but is yet to be analysed. Of particular interest will be the hypoglycaemia rates, as several studies have reported that in intensive insulin programmes hypoglycaemia rates were either unchanged or decreased (Mulhauser et al, 1987; DAFNE Study Group, 2002; Plank et al, 2004). Anecdotal reports from the participants during and following ASPIRE indicate that hypoglycaemic episodes are experienced less frequently. This potential benefit requires further investigation, particularly as the fear of this complication often impedes the attainment of good diabetes control.

Conclusion

In absolute terms, it is not possible to define which aspects of ASPIRE had the greatest effect or indeed how easily the observed effects might be transferred to the wider population with type 1 diabetes. However, the results show that intensive insulin skills training programmes can be adapted from national models and be successfully implemented locally. Long-term data is required in order to establish whether these outcomes can be sustained to the 12-month period and in the longer term. Although small, the current study adds to a growing body of evidence that suggests providing skills training programmes for adults with type 1 diabetes leads to improved outcomes. Furthermore, these educational approaches have the potential to minimise, if not prevent, the incidence of diabetes-related complications and this warrants further investigation and investment. ■

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