It’s education, Jim, but not as we know it

The Janet Kinson lecture is given to celebrate what has been achieved in diabetes education. This article expands on some elements of diabetes education in which I have been involved while working at King’s College Hospital, London.

It begins with DAFNE, then moves on to the instigation of a different delivery model: the Hub and Spoke DAFNE; next, the research I undertook with people with impaired awareness of hypoglycaemia, and the subsequent course that arose from that research – named HARP (Hypo Awareness Restoration Programme). Lastly, it touches on some new ways of working that are being researched at the moment – new forms of education for me.

Background

Picture this: a diabetes department in a lovely characterful house, with a fig tree in the garden, next to the hospital in Palmerston, North New Zealand. I began working there in the early 90s. When Professor Stephanie Amiel came to New Zealand to talk at one of the national diabetes conferences, I was completely wowed by her, so imagine my excitement when the word came that King’s College Hospital had a locum position available. I have been able to work with superb colleagues; Eileen Turner was the Nurse Lecturer/Practitioner, and later to become King’s Diabetes Department’s first Nurse Consultant. She set the scene for the fabulous nurse specialists at King’s to be questioning, learning and putting new ideas into practice.

DAFNE

In 1998, I was part of a delegation from King’s, Sheffield and North Tyneside that went to Dusseldorf to observe a DAFNE course in action (of course with our German interpreter). What absolutely struck me about the Michael Berger group was their desire to set people with type 1 free from the burden of restricted carbohydrate and strict timings of meals and snacks. How strange that sounds to us now, but, embarrassingly I recall, that was how we taught people with type 1. The Berger insulin treatment model was primarily to emancipate people with type 1 diabetes from the shackles and set them free to use insulin to match carbohydrate.

That visit of the DAFNE group to Dusseldorf is well known, along with our original scepticism. However, we saw first hand that they had not handpicked the participants and that actually one of participants struggled to grasp the concepts and algorithms – it was so reassuring that it was not just their showcase patients. And we saw how ratios and twice-daily background insulin meant people could eat – when and what (mostly) they liked. Their HbA1c improved, they did not put on weight, and, despite those improvements, they had less severe hypoglycaemia. This was different from any other education course around. We resolved to bring the course to the UK. After a year of translating the course and resources and debating among our group about keeping the course as close to the original Dusseldorf programme as possible, we were able to carry out the first research trial of DAFNE in the UK in the year 2000. It worked – glycaemic control improved significantly and severe hypoglycaemia also improved. And these effects have been shown to last for at least 42 months after a DAFNE course.

Since the initial DAFNE research in 2000, the DAFNE research programme has continued – this has included a database, qualitative research led by sociologists, health economics by economists, health psychologists, DAFNE graduate groups and other disciplines all joining in the DAFNE research programme to make DAFNE what it is today. The research programme has meant that we have been able to answer important questions: is there a way of determining who is likely to do best, does DAFNE work outside the research situation, for how long are benefits maintained, and what (mostly) they liked. Their HbA1c improved, they did not put on weight, and, despite those improvements, they had less severe hypoglycaemia. This was different from any other education course around. We resolved to bring the course to the UK. After a year of translating the course and resources and debating among our group about keeping the course as close to the original Dusseldorf programme as possible, we were able to carry out the first research trial of DAFNE in the UK in the year 2000. It worked – glycaemic control improved significantly and severe hypoglycaemia also improved. And these effects have been shown to last for at least 42 months after a DAFNE course.2

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what do people with type 1 say about the course, what could be done better, and what are the costs?

Dr Debbie Cooke’s investigation is an example of the work done as part of the research programme. We wanted to determine whether there were subgroups who would be more likely to benefit from, or struggle with, DAFNE training.

We looked at many variables (see Box 1). A multivariate and univariate analysis was used to see if these factors predicted change in HbA1c, but these demographics together and on their own had minimal explanatory value in terms of predicting HbA1c at follow up. The conclusion drawn from that study was that screening people prior to undertaking structured education is unwarranted.

We needed to know this; otherwise structured education might have always been relegated to those with higher education or those who had a high degree of self-efficacy.

Outcomes: does DAFNE work outside the research setting?
Following on from the initial research in 2000, the data that have been collected over subsequent years, in the real world, have been able to demonstrate the continuation of results very similar to those of the original research.

For those with baseline HbA1c >69mmol/mol (8.5%) mean reduction was -8.7mmol/mol (-0.76%) while weight remained unchanged. The mean severe hypoglycaemia rate fell from 7.8 to 2.2 episodes/year, showing for the first time that screening people prior to undertaking structured education is unwarranted.

We found that the number of emergency treatments decreased for ketoacidosis and also for severe hypoglycaemia. In her study cohort of 939 patients, the cost of emergency treatment fell by 64%.

NICE’s review of the DAFNE evidence estimated that full implementation of the programme could save the NHS £48 million/year in reduced admissions and complications. The Quality, Innovation, Productivity and Prevention Programme (QIPP), under the auspices of the Department of Health, cited DAFNE as being one of the top 10 most effective examples of quality and productivity improvement in the NHS.

The all-inclusive costs for centres delivering one course a month worked out at approximately £55 per patient per year. DAFNE currently runs programmes of either five consecutive days or one day a week over five weeks. Can we do it even more efficiently? Professor Angus Forbes and colleagues scoped the current delivery systems of diabetes healthcare in the UK. They state that reducing the amount of time spent on structured education reduces the impact of the education. There was poorer performance of a condensed version of a programme which ran over 2.5 days, compared to the programme which ran over five days.

We have learnt that DAFNE costs more than pays for itself – the outcomes are consistently better than without DAFNE.

Quality assurance
We have been able to prove that DAFNE centres are able to maintain the quality of DAFNE over many years. This has been achieved by having a robust quality assurance programme. It has been my privilege to be one of the DAFNE educators to the educators. The aspects that we have delineated to observe when we go and peer review at other centres have been developed alongside Ofsted inspectors, with whom we collaborated when we first started DAFNE; it was embedded well at the very beginning of DAFNE. The three categories that are measured are:

• Ensuring all of the knowledge is passed on: sick day rules, hypoglycaemia, the annual review parameters and meanings.
• Ensuring the educator is able to apply the dose adjustment algorithms and carbohydrate counting skills so that participants can become expert in these skills.
• Ensuring that the educator uses adult education principles, the DAFNE philosophy, and has the associated behaviours when delivering the course.

I am very glad that we recognised how essential it is to measure the educator’s attributes. When we are peer reviewing, we get to see the educator’s great skills in: facilitating; counselling; sensing when someone hasn’t got it; congratulating someone for making a change; knowing how to bring quiet members of the group into the session; knowing how to shut the noisy ones up. These skills are crucial, and DAFNE educators recognised, from the beginning, that they are vital.
Experience of the DAFNE programme

- The DAFNE programme can be for all
- Biomedical and quality of life outcomes improve, even up until 4 years
- DAFNE more than pays for itself
- A 5-day course is efficacious
- Quality assurance improves outcomes
- The Hub and Spoke model of delivery is effective
- DAFNE graduates valued the group, the knowledge and the educators

Box 2. What we have learnt from DAFNE

<table>
<thead>
<tr>
<th>Group 1 – high concern</th>
<th>Group 2 – low concern</th>
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<tr>
<td>Wish to regain awareness</td>
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<td></td>
<td>(a) Normalising IAH</td>
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<tr>
<td></td>
<td>(b) Underestimating the effects of IAH</td>
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<td></td>
<td>(c) Avoiding the sick role</td>
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<tr>
<td></td>
<td>(d) Overestimating high glucose</td>
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</table>

Table 1. Results of research into perceptions of people with impaired awareness of hypoglycaemia

ingredients to ensuring the structured education course works.

The Hub and Spoke model of DAFNE

We were receiving a large number of referrals from district general hospitals (DGHs) near us which did not have the staffing capacity to run DAFNE themselves, and while we had capacity to deliver the DAFNE courses, it would have been difficult for us to deliver the follow up for their patients at King’s. I proposed that we adopt a Hub and Spoke model to address this, and carried out the research accordingly. We offered to provide DAFNE courses for people with type 1 from three DGHs around our area, and to train their educators to continue the follow up. The aim of this research was to see if the outcomes would be as effective as the original DAFNE despite the different mode of delivery. The results showed that HbA1c fell by 0.7% among those who had HbA1c >58mmol/mol (7.5%) at baseline.

It was the first of the DAFNE research studies to show a statistically significant fall in severe hypo-glycaemia, and, once again, all of the quality of life data improved significantly. However, one of the most rewarding parts of running the DAFNE Hub and Spoke research was that the three DGHs recognised the benefits and enjoyed the process so much that they changed their service delivery in order to be able to run DAFNE themselves. Unintended consequences, but a very good outcome.

We learnt that education can be provided by different models of care, and using a Hub and Spoke model can mean that more people with type 1 are able to access essential education.

What about the participants?

What do they think of DAFNE?

Professor Julia Lawton and Dr David Rankin have done excellent qualitative research within the DAFNE research programme. One of their qualitative studies was carried out with the DAFNE graduates asking about their understanding and experiences. The three main themes that arose from their research as to why the DAFNE course was successful were: (1) the group setting (despite the participants thinking that they would not like the group); (2) the knowledge they gained; and (3) they really appreciated the educators!

Box 2 provides a summary of all of the things learnt from the DAFNE programme.

Impaired hypo awareness, and the HARP course

Because of Professor Amiel and Dr Pratik Choudhary, impaired awareness of hypoglycaemia (IAH) has been at the forefront of research at King’s College Hospital.

IAH is when the usual autonomic symptoms experienced, such as sweating and trembling, do not occur until blood glucose is lower than 3.0mmol/L (whereas they occur between 3 and 4mmol/L when people have hypo awareness).

This is critical, because when the glucose level is lower than 3mmol/L the brain is unable to maintain certain functions such as reaction time, accuracy or speed of decision making, and so the person is rendered at high risk of harming themselves – especially because, while hypo, they feel fine. IAH leads to a six-fold increased risk of having a severe hypo.

Our King’s group established that there is a particular brain mechanism involved with IAH. In hypo aware patients there was an appropriate stress response. However, the patients with IAH had no stress response; on the contrary the reward areas of the brain are not switched off. People with IAH are not only not aware that they are experiencing a hypo, but they are also unaware of the negative aspects to it.

We know from the research carried out at King’s and other groups that IAH can be restored by rigorous avoidance of hypoglycaemia for a period. We also know that education plays a part in the restoration. The DAFNE audit demonstrated that. However, there remain those for whom IAH is more problematic and for whom a new paradigm of education is needed. Because there was no existing research into what the people with IAH were thinking and experiencing, I set out to investigate this.

My research involved interviewing people with IAH and a history of severe hypoglycaemia. I listened to harrowing tales of severe hypoglycaemia. All participants recounted numerous stories which caused them absolute distress to recall.

You could hear the embarrassment that came from having to recount their stories; indeed, the participants regarded these episodes with horror. So why was it that these participants did not translate this horror into avoiding hypoglycaemia and restoring hypo warning signs? My research was to ask people with IAH and severe hypoglycaemia what lay behind their action or inaction.
By interviewing and constantly comparing their transcripts to discover the emerging theory, I was able to ascertain five different groups of beliefs that explained the behaviour of people with problematic IAH. (See Table 1.)

In Group 1, only four of those who were interviewed expressed congruency between what they felt about the severe hypo episodes and the behaviours they had put in place to try and overcome the hypo unawareness.

The remainder of the 17 participants – Group 2 – all expressed a desire to eliminate severe hypoglycaemia and its causes, but their actual behaviour showed no corresponding effort to do so. This is termed cognitive dissonance – what we say, does not match our behaviour.

After recognising that there was this cognitive dissonance, I was then able to drill down into the detail of their stories and elicit the common cognitions that contribute to people maintaining impaired awareness of hypoglycaemia.

Group 2a: people in this group – normalising impaired awareness of hypoglycaemia – had come to think of having no warning signs and of the severe hypoglycaemia that ensued as something that was a normal part of life for them.

They were able to state that, when they experienced a severe hypo, who was going to help them, and how that was a perfectly normal part of life. Because these hypos were being dealt with by others around them and each person around them knew their role in how to treat the severe hypo, that meant that things were OK.

One lady explained that, when she was at the golf club rooms after golf, the barman would say, ‘Here, get that down you’ and would plonk a glass of lemonade in front of her. The barman knew she was hypo, even though she didn’t – she didn’t have to change her behaviour, because those around her knew how to deal with it, and even if she had a severe hypo, the club members knew how to ‘bring her round’. Hypos and even severe hyps had become part and parcel of normal life.

<table>
<thead>
<tr>
<th>Thinking traps</th>
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</thead>
<tbody>
<tr>
<td><strong>The ostrich – burying one’s head in the sand:</strong></td>
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<tr>
<td>• ’I’ll be OK’</td>
</tr>
<tr>
<td>• ’I don’t need to worry about it’</td>
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<tr>
<td>• ’It’ll never happen to me’</td>
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<tr>
<td><strong>The soldier – soldiering on:</strong></td>
</tr>
<tr>
<td>• ’I don’t want to make a fuss’</td>
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<tr>
<td>• ’I don’t want to bother/inconvenience people’</td>
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<tr>
<td>• ’I don’t want to feel weak/silly’</td>
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<tr>
<td><strong>The over-sensitive smoke alarm – predicting the worst-case scenario:</strong></td>
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<tr>
<td>• ’I must be in target all the time’</td>
</tr>
<tr>
<td>• ’It’s better to run low than high’</td>
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<tr>
<td>• ’I can’t stand seeing high blood sugars’</td>
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</table>

The next category was very similar to the first: those who underestimated the effect of hypoglycaemia on themselves and those around them. There was an example of one gentleman who had had more than one car accident while hypo, and in the last one he had dislocated his ankle and had lost his licence, but his main concern and anger was that he had lost his licence. When I asked him about this, ‘Why do you think the authorities might be worried? You had someone in your car, and they could have been injured’ (it was his boss), he was cross with my question and said, ‘Well it’s not going to happen again; that was an exceptional circumstance.’ He was definitely underestimating the effect of hypoglycaemia.

The next category of thought was (and people could have more than one area of cognitive dissonance at one time) avoiding the ‘sick role’; this involved not wishing others to know that they were debilitated by hypoglycaemia. They mentioned how important it was for others around them to see that they were coping and how they did not wish to be wrapped in cotton wool and treated differently.

An example from one participant: ‘If I have a bad hypo on my own, I won’t tell, or say, “oh I had another hypo the other night” ’cos I know their reaction is “(tut) he’s not taking care of himself,”’ that sort of thing. So I’m a bit sort of closeted about them.’

The last category identified are the people that we as health care professionals are able to recognise most easily. These are people with type 1 who overestimate the effect that hyperglycaemia will have on their lives; they work extra hard to keep the glucose levels from going high and allow the glucose levels to go below target many times during the week because of their fear of long-term complications.

These cognitive dissonances discovered were a new aspect of IAH. Our team discussed these findings and Dr Nicole de Zoysa (clinical psychologist colleague) developed a programme to enable people with IAH address these thought patterns. (It is not just people with IAH who have cognitive dissonances: we all have them.) The programme developed was named HARP (Hypo Awareness Restoration Programme).

Dr de Zoysa also developed a two-day training programme for educators, training us to use the principles of motivational interviewing and cognitive behavioural therapy – new developments in our educational skills. Sheffield educators joined with King’s College Hospital educators to run a pilot programme.

The cognitive dissonances I had identified, Dr de Zoya termed ‘thinking traps’ and used visual aids to assist the participants to identify their own. She combined the first two and came up with three thinking traps, See Box 3.

Participants all identified with at least one thinking trap, and they were given help to work out how the thoughts of that particular trap maintained the vicious cycle of IAH. Then they were given help to design ways in which they could most easily break the cycle. They had time to think about the pros and cons of maintaining how they were, and the pros and cons for changing, and then time to come up with different sentences that could break the cycle. (See Table 2 for the course structure.)

The following are some examples of the different sentences the patients came up with for the person identified as having a ‘soldiering on’ thinking trap.
Sometimes diabetes needs to take centre stage: ‘Attending to mild hypos will cause less embarrassment and distress than a severe hypo’: ‘Your performance may be affected without you even realising it’: ‘Taking action to protect your warning signs is a sign of strength not weakness.’

Results of HARP

Twelve months after HARP, hypoglycaemia awareness improved; median rates of severe hypoglycaemia fell dramatically. HbA1c was unchanged – 61±14mmol/mol versus 62±13mmol/mol, p=NS.15 See Table 3.

The course and the results were impressive, especially given that this group had seemed to have irreversible hypo unawareness. We would love to be able to roll it out so that it is available for all, and we are exploring ways of doing this.

What we have learnt: the HARP programme leads to sustained improvement of hypoglycaemia awareness and reduction of severe hypoglycaemia in people with type 1 diabetes and previously intractable impaired hypoglycaemia awareness. Educators were able to learn and deliver these models of behaviour change – motivational interviewing and cognitive behavioural therapy. Patients valued the chance to talk together about these cognitions and grasped the concepts well.

What is the next frontier?

In delivering the HARP course, we educators had to learn new skills to be able to facilitate the course. It did feel like a new frontier: it was strange to use motivational interviewing and cognitive behavioural therapy; skills involved rolling with resistance, looking for green shoots of understanding, examining ambivalence, exposing dissonance. It felt so hard at the beginning and it still does not come naturally. This is what I meant when I said, ‘It’s education, Jim, but not as we know it.’ We have been learning a new paradigm of delivering education for the benefit of people with type 1 – one that we believe can be rolled out as routine practice.

Armed with these new skills, the DAFNE research group is embarking on revisiting some of the core principles that are embedded in the DAFNE curriculum and teaching styles. The DAFNE group has procured a major funding grant to pursue this – it is called DAFNENplus. In collaboration with the qualitative scientists Professor Lawton and Dr Rankin, a behavioural scientist – Professor Susan Michie from University College London – will be joining us. We have technology wizards, including a lot of DAFNE graduates, doctors and educators, and we aim to embark upon the next phase of work to improve DAFNE in the many areas that still need addressing.

Let’s all of us boldly go... and learn some new education skills for our next adventure.

Table 2. HARP (Hypo Awareness Restoration Programme) course outline

<table>
<thead>
<tr>
<th>Week no.</th>
<th>Session</th>
<th>Topic/activity</th>
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<tbody>
<tr>
<td>One</td>
<td>Group session (9.00–4.30pm)</td>
<td>How low can you go?</td>
</tr>
<tr>
<td>Two</td>
<td>Group session (9.00–4.30pm)</td>
<td>The balancing act</td>
</tr>
<tr>
<td>Three</td>
<td>Group session (9.00–4.30pm)</td>
<td>Thinking traps</td>
</tr>
<tr>
<td>Four</td>
<td>Individual face-to-face appointments (1 hour)</td>
<td>Review progress and problem solving</td>
</tr>
<tr>
<td>Five</td>
<td>Individual phone appointments (45 mins)</td>
<td>Review progress and problem solving</td>
</tr>
<tr>
<td>Six</td>
<td>Keeping on track (9.00–4.30pm)</td>
<td>Review of course and maintaining progress; invitation to significant others</td>
</tr>
</tbody>
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Table 3. Results of HARP (pilot)

<table>
<thead>
<tr>
<th>Hypoglycaemia</th>
<th>Baseline</th>
<th>12-month follow up</th>
</tr>
</thead>
<tbody>
<tr>
<td>Severe</td>
<td>3 (0–104)</td>
<td>0 (0–3)</td>
</tr>
<tr>
<td>Moderate</td>
<td>14 (0–100)</td>
<td>0 (0–18)</td>
</tr>
</tbody>
</table>

References