

Patients' experiences of, views about and perceived needs for support when implementing flexible intensive insulin treatment: a qualitative longitudinal study



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D Rankin¹, D Cooke², M Clark², S Heller³, J Elliott³, J Lawton¹
for the UK NIHR DAFNE Study Group

Centre for Population Health Sciences, University of Edinburgh¹, Dept of Epidemiology and Public Health, University College London²
Academic Unit of Diabetes, Endocrinology and Metabolism, University of Sheffield³



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Introduction: Many structured education programmes (SEPs) for patients with type 1 diabetes provide education/training to enable them to use flexible intensive insulin treatment. This regimen involves the use of quick acting (QA) insulin boluses injected to cover meals/snacks, along with a background insulin (BI) generally administered twice daily to control blood glucose (BG) between meals. Type 1 diabetes patients graduating from SEPs experience short-term (6 months) improvements in glycaemic control, quality of life and dietary freedom; however, this is followed by deterioration in glycaemic control over time. It is unclear what support would most help patients using flexible intensive insulin treatment to sustain improvements in biomedical outcomes over time.

Aims: To explore the support needs of type 1 diabetes patients after attending a SEP providing training in use of flexible intensive insulin treatment.

Methods: A longitudinal qualitative investigation was undertaken involving 30 type 1 diabetes patients converted to flexible intensive insulin treatment, recruited from six Dose Adjustment for Normal Eating (DAFNE) courses in the UK. Repeat in-depth interviews were conducted at baseline (on completion of courses), 6 and 12 months.



About DAFNE and the provision of flexible intensive insulin treatment training

DAFNE is a group-based SEP, delivered over 5 consecutive days, which provides training in flexible intensive insulin treatment for type 1 diabetes patients in the UK. Using a standardised curriculum, patients are instructed how to count carbohydrates and, using algorithms (ratios), to calculate optimal QA dosages based on amount of carbohydrate ingested. Calculations also take into account pre-meal self-monitoring of blood glucose and lifestyle factors. Patients are encouraged to maintain BG within specific target ranges and, using diary records, look for patterns in BG readings to ascertain whether changes are required to BI doses and/or QA mealtime ratios. Whilst patients make changes to their BI doses and QA ratios during DAFNE courses, they are instructed, when necessary, to make further alterations over time. DAFNE courses are normally facilitated by two educators – a diabetes specialist nurse and a dietitian. Patients are invited to attend a group-based, half-day follow-up session 6 weeks after their course has ended.

Results 1: Technical support from trained personnel

While flexible intensive insulin treatment was described as a logical and effective approach, this was also considered to be a technically complex regimen. Hence, patients highlighted a need for on-going input and technical support from appropriately trained staff. In some cases, patients sought reassurance after making alterations to their QA ratios or BI insulin doses. More typically, patients described being uncertain about their interpretations of patterns in BG readings and, hence, of needing advice, or an opportunity to trouble-shoot concerns, before making alterations:

"I've sort of said, 'should I put my background up one, it's going high here?' And she's [educator] like, 'well, give it until the end of the week, you know, let your body settle down a little but don't do too many changes too quickly'".

Results 2: Experiences of seeking support from health-care professionals

Patients described course educators as their first "port of call", and of receiving unsatisfactory support from alternative sources: *"because they [GP] haven't heard of DAFNE"*.

Patients reported how clinicians providing routine hospital check-ups placed most emphasis on HbA1c readings, rather than offering a holistic appraisal that many had received, and come to expect, when attending a DAFNE course:

"she [consultant] said, you know, 'yeah, your A1c's fine, we're all happy with that, let's check your feet quickly, eh, was there anything else, no problems, right, cool, there you go, out you go'"

Despite having concerns about making dose adjustments patients were often reluctant to initiate impromptu contact with clinicians as they did not wish, or did not feel they had the right, to burden staff outwith routine appointments.

However, patients who were able to engage in regular contact with educators, described benefiting from receiving technical advice and personalised support:

"...basically I was doing a little bit of exercise and I was talking to [the educator] about what was happening with the readings and they suggested I should try to reduce it [BI]".



Results 3: Organised follow-up

Patients recalled difficulties attending DAFNE follow-ups:

"I didn't go ... I was slightly busy at work, knew that I had my annual review coming up anyway... and retinopathy screening and I thought, I'm not asking for any more afternoons off work".

Despite low rates of attendance, follow-up sessions provided patients with opportunities to: seek peer support: *"it was reassuring to find out that other people are having the same problems as you"*; boost motivation when *"the novelty has worn off"*; and, receive appraisal from trained staff to check *"if, you know, [educators] thought that we were doing alright"*.

However, in general, patients were disappointed with group-based follow-up because:

"everyone's an individual and I think everyone has individual needs".

Patients described needing on-going support, available on an 'as and when' needed basis, tailored to address their personal and specific experiences of using flexible intensive insulin treatment in everyday life:

"one of the things that prompted me to sort of up the ante [with educators] ... was my

lifestyle's changed on more than one occasion... I've spent a year working out in the field ... and my dosages changed big time, eh, me diet changed big time"

Results 4: Organised follow-up

To obtain treatment-specific reassurance, technical support and trouble-shooting opportunities, and to access help as and when it was needed, patients suggested establishing a dedicated *"emergency line"* or *"twenty-four hour helpline"*.

To avoid over-burdening staff, patients suggested that support services be delivered: by *"somebody who was just 100% DAFNE"*; and, using a *"structured appointment system"* as this *"would make it easier to approach them [educators] rather than being left to just approach as an individual"*.

Conclusions:

- To maintain the clinical benefits of SEPs over time, on-going support from trained staff should be offered to patients on an 'as and when' needed basis.
- Patients articulated a need for support to be tailored and personalised to reflect their specific and unique experiences of putting flexible intensive insulin treatment into practice in the context of their everyday lives.
- A 'menu' of support could be developed, which takes into account alternative forms of provision (e.g. telephone-based support).
- Support for flexible intensive insulin treatment should be offered as an integral part of a patient's care package and, hence, as something that they are expected and entitled to ask for.