

THE PAPER THAT CHANGED MY LIFE

Making research into complex educational interventions respectable



Simon Heller

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In the 1980s I was fortunate to train in a centre that promoted a patient-centred approach and encouraged us to reflect on our practice. I soon realised that fiddling with the insulin dose or haranguing patients to improve control had little effect and that few patients were actively engaged in self-management. I concluded that the limitations of insulin delivery and the risk of hypoglycaemia meant that intensive insulin therapy was too arduous for all but a few obsessional individuals. My consultations were largely spent commiserating patients about how difficult diabetes was to live with, reassuring them about poor glycaemic control and supporting them when they developed complications.

However, in the mid 1990s, I was roused from my nihilism by Ingrid Mühlhauser and Michael Berger from Düsseldorf. They were scathing about the standard of intensive insulin therapy undertaken in many countries, including the Diabetes Control and Complications Trial (DCCT Research Group, 1993). They claimed that glycaemic control could be improved while reducing rates of severe hypoglycaemia by ensuring that patients acquired the skills in insulin self-management. As somebody with a research interest in hypoglycaemia I was intrigued by what I perceived as the arrogance of this counter-intuitive statement. I investigated whether they had formally evaluated their approach and was startled to find that they had published their results in a high-quality journal. Their most influential paper was published in *Diabetologia* in 1987 (Mühlhauser et al, 1987). They trained local healthcare teams in Rumania, then behind the Iron Curtain, to deliver a one-week structured insulin treatment and training programme (ITTP). Groups with type 1 diabetes were allocated either to receive basic information only, attend the ITTP or receive usual care for 12 months before receiving the intensive intervention. The results were impressive. Following the ITTP, HbA_{1c} fell by 2% and was sustained for two years compared to controls whose HbA_{1c} initially remained unchanged and then improved by the same amount after they undertook the ITTP. Those receiving basic information had only a modest and unsustainable improvement in glycaemic control, indicating that the provision of skills in addition to ‘knowledge’ gave significant added benefit. Furthermore, improved glycaemic control was accompanied by considerably less severe hypoglycaemia.

The study had limitations; the randomisation process was flawed and the participants were starting from such a low level of knowledge that almost any intervention would have led to improvement. However, the sustained fall in HbA_{1c} was far better than we achieved locally and indicated that structured education providing the skills to self-manage diabetes was far more successful than the opportunistic unstructured input that we and most diabetes centres traditionally provided.

This paper and a memorable visit to Düsseldorf, where we saw for ourselves just how much patients valued the approach, has changed not only my life and those of my colleagues in North Tyneside, Kings and Sheffield, but more importantly that of many of our patients. The subsequent Dose Adjustment For Normal Eating (DAFNE) trial demonstrated that the approach could be delivered in a UK setting and produced major improvement in quality of life (DAFNE Study Group, 2002). There is now a growing acceptance that those with diabetes need skills as well as knowledge to manage their disease successfully and that diabetes units should be providing all patients with the opportunity to acquire them. It is also increasingly understood that the development of educational interventions should be based on high quality research and that such research is difficult and requires adequate funding and training.

The Düsseldorf unit deserve immense credit for undertaking such pioneering work. They have demonstrated that this type of research can be published in the best journals, can change practice internationally and – unlike many other fields – leads to improved patient care within the lifetime of the investigators.

DAFNE Study Group (2002) Training in flexible, intensive insulin management to enable dietary freedom in people with type 1 diabetes: dose adjustment for normal eating (DAFNE) randomised controlled trial. *British Medical Journal* **325**: 746–49
DCCT Research Group (1993) The effect of intensive treatment of diabetes on the development and progression of long-term complications in insulin-dependent diabetes mellitus. *New England Journal of Medicine* **329**: 977–85
Mühlhauser I, Bruckner I, Berger M et al (1987) Evaluation of an intensified insulin treatment and teaching programme as routine management of type 1 (insulin-dependent) diabetes. The Bucharest-Düsseldorf Study. *Diabetologia* **30**: 681–90

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