Patient education and diabetes care: Part 2

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Today's diabetes world is fast-moving and exciting; knowledge is accumulating at an astonishing rate. To help understand the present, however, it sometimes helps to examine the past.

In this installment of *Tattersall's Tales*, Robert Tattersall gives the second part of a two-part series tracing the history of patient education, highlighting the importance of language, psychology and a person's social environment in determining outcomes in diabetes.

"It has been my experience that most cases of diabetes will cooperate if given the right kind of help. I know of no disease where individualisation in management is so important as in diabetes and in no chronic disease are we so well rewarded for our efforts in management." Willard C Stoner (1924).

To avoid any misunderstandings let me say at the outset that I have always firmly believed that people with diabetes need to be taught how to manage their condition (education). Nevertheless, in 1992 I wrote an article entitled "Why doesn't education work in IDDM?" (Tattersall, 1992). This article, which was vilified and praised in equal measure, was prompted by a well-designed study in Holland in which 12 hours of "education and motivation" in 355 people with type 1 diabetes for an average of 12 years failed to produce any improvement in metabolic control, quality of life or cost of treatment (de Weerdt et al, 1991). This was by no means the first study to show no benefit from education (or re-education, which is what it really was). Many previous trials had shown that education improved knowledge but rarely, if ever, glycaemic control.

Elliott Joslin suggested that clinic visits should "never be perfunctory and never be for diabetes alone". They should be an opportunity for continuing education (Joslin, 1949).

I do not know how good Joslin was at communicating with his patients but many efforts of us ordinary mortals are thwarted by what Gérard Reach calls linguistic barriers (Reach, 2009). The example Reach uses in his scholarly article is that of a Chinese woman who does not speak French but his argument is equally valid in cases of language concordance. A particularly gross example is one of my failures. In 1976, as a new consultant, I broached the subject of impotence with a Nottingham miner. I began with a direct question "are you impotent?" to which he replied "wot?". I tried again with "do you have satisfactory sexual relations?" to which he again replied "wot?". My third attempt was with "can you get an erection?" which was met with the same answer. Finally I decided on the vernacular and said "does your cock get stiff?". "Good heavens," he said " is that what you've been trying to ask me? Yes, it does, although the missus isn't very keen on that sort of thing". I remember that our Nottingham Professor of Medicine, Tony Mitchell, used to show the new students a slide on which he listed the vernacular words for common bodily functions and exhorted the students to use them with appropriate patients.

Back to diabetes education. In 1992 I had reviewed glycated haemoglobin concentrations in 300 people with diabetes in my clinic over 10 years and found that most appeared to be "stuck in tramlines". In other words, HbA_1 – whether normal, moderate or high – at the beginning was likely to have a very small standard deviation over the decade in spite of much professional input and many changes of insulin and other factors. Where metabolic control was concerned there appeared to be powerful inertial forces maintaining the *status quo*. The same was, perhaps less surprisingly, true of weight.

These findings prompted me to ponder the question of why it was so difficult to change the trajectory of individuals with diabetes? In the first instance, it seemed self-evident that education would only be of benefit in those whose problem was ignorance, although some diabetologists seemed to think that the solution for every person with poor control was, in Tony Blair's words, "education, education and education".

In a 1985 article which, even today, all aspiring diabetologists ought to be made to read, the leading lights of the education section of the European Association for the Study of Diabetes pointed out that the care of people with diabetes was not simple and that "long-term metabolic control is the consequence of a complex process simultaneously involving psychological, endocrine and pharmacological factors" (Assal et al, 1985). The lead author of this article, Jean-Phillipe Assal of Geneva, had done workshops with physicians and found that many, although paying lip service to the concept of empowering patients, consciously or subconsciously acted like dictators and were not prepared to tolerate mistakes made by people with diabetes during self-management. These "old fashioned physicians" who kept their patients in straight jackets were not, according to Assal, team players and had "almost total unawareness" of the need for specific training in patient education.

So, the unequal power of the doctor–patient relationship was one potential block. In the 1980s an American physician, Sheldon Greenfield, hypothesised that in an ideal world each person with diabetes would actively negotiate with their doctor to arrive at a treatment plan that would best suit their circumstances and personality. His intervention was, half an hour before their clinic appointment, to train patients in self-assertiveness in the hope that they would actively negotiate medical decisions with the doctor. This reduced HbA_1 from 10.6% to 9.1% in the self-assertiveness group with no change in controls (Greenfield et al, 1988).

In my 1992 article I pointed out that a sure way of improving glycaemic control was to enrol people with diabetes in a trial because, in my words, “in these self-selected volunteers, control improves more in the run-in period than subsequently with whatever is being tested”. Naturally I would not expect this *ex cathedra* pronouncement to be accepted without evidence and I was glad to see that 15 years later my erstwhile colleague Edwin Gale confirmed the effect and quantified its magnitude (Gale et al, 2007). As one would expect, the fall in HbA_{1c} was greatest in those with the worst control, so that someone with an HbA_{1c} level of 11.9% (107 mmol/mol) would be likely to have a fall of nearly 2% after 70 days.

The problem in my clinic was that people with HbA_{1c} levels >11% (>97 mmol/mol) would only have “volunteered” for a study if it spared them a prison sentence or somesuch. The serious message from the Gale study is that after the first year or two management of diabetes becomes very boring – what Joan Hoover called 365 days a year without holidays – and may lead to burnout (Hoover et al, 1983).

In my article I referred to a fascinating Swedish article on tedium among people with type 1 diabetes (Lundman et al, 1988). Tedium (or burnout) is a concept that was originally developed in relation to working environments, with high levels of tedium expressing themselves, *inter alia*, as negative self-concept, negative attitudes, irritability and resistance to change. Interestingly the highest levels of tedium were found in people with the best and worst glycaemic control. One cause of tedium is the setting of what the individual sees as impossible goals so that they simply give up. Others give up because they are unable to give priority to their future.

Personality and the patient’s psychosocial milieu are, to my mind, crucial determinants of outcome in diabetes. I used to find that after the first interview with a newly diagnosed individual, I more or less knew how well they were going to manage their diabetes during the coming years. For example, a 10-year-old boy from a broken home and already diagnosed as having attention-deficit hyperactivity disorder would most likely do badly. As Gérard Reach puts it, the choice that the person with diabetes has to make every day is between “a larger delayed reward for adherence (freedom from complications) and a smaller but more immediate reward for non-adherence, e.g. an extra portion of cake, the forbidden cigarette, avoiding the boring task of looking for the tablets, avoiding the side effects of the medication” (Reach, 2010). The ability to delay gratification is an important lesson for children to learn and is the problem for the 10-year-old boy cited above.

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