

Patient involvement in diabetes care: Walk the walk



Brian Karet

We are doing pretty well looking after patients with diabetes. Data from the QOF (<http://www.qof.ic.nhs.uk/>), the government's clinical target system, shows sustained year-on-year improvements in proxy outcome measures. Patients seem pleased and report excellent communication with medical staff and high levels of satisfaction with treatment when patient-centred care is delivered in the community (Kinmonth et al, 1998).

Over many years, the government has made it clear that the bulk of diabetes care should be provided in the community, starting with the 2000 NHS plan and progressing with 'Our health, our care, our say' in 2006 (DoH, 2006a), which was based on an extensive public consultation exercise. So, not only do commissioners of care, mainly PCTs, have the direction of travel of diabetes care, but, with the publication last year of the Diabetes Commissioning Toolkit (DoH, 2006b), also the mechanisms to implement it. Apart from all the professional input, patients were also heavily involved in the construction of this really useful document.

It comes as a bit of a surprise then that almost 7 years on from the Diabetes NSF, the Healthcare Commission (2007), looking at diabetes care from the patients' perspective, still rates only 16% of trusts in England as excellent or good. They noted large variations not just in clinical outcomes but in screening and access to education. It was commented that if the healthcare professionals involved in diabetes care, from the acute hospital to the ambulance services and general practices, worked together in a multidisciplinary network, there should be a much lower emergency admission rate as a result of diabetes complications, particularly diabetic ketoacidosis. The Commission found that in 95% of PCTs, there is scope to reduce the number of emergency admissions to hospital

for diabetes-related complications. Between 2003 and 2006, emergency admission rates fell in only eight PCT areas.

Maybe this shouldn't have come as too much of a shock and, to some extent, it is the QOF that is at fault. Diabetes care is all about understanding the chronicity of the condition and minimising future risk. It's about engaging patients not just at a personal level, but also at a system level. However, we have ended up with diabetes care that looks increasingly like a factory conveyor belt producing identikit crash dummies that are only allowed to see the light of day when all the numbers on the front are within acceptable tolerances. It seems increasingly evident that the only way to achieve all these targets is with the use of more and more drugs that may reduce an individual's risk but, at the same time, certainly reduce their quality of life.

Qualitative studies suggest that patients value autonomy and equality in the care planning of their diabetes, over being shoehorned into the healthcare professional's vision of good diabetes care (Hornsten et al, 2005). This is just one of many reasons that people with diabetes feel dissatisfied with clinical encounters. Not only do they often not share our motives, but they don't share our objectives either. A fascinating study of people attending community-based diabetes clinics in Chicago (Huang et al, 2007) looked at the quality-of-life impact (measured as utilities) of both diabetes treatments and the ensuing complications. Not surprisingly, more serious complications, such as major stroke, had lower utility scores (for example, a lower quality-of-life score) than less serious complications such as minor stroke, but some intensive treatment regimens, particularly involving multiple injections of insulin, had utility scores as low as the complications of diabetes.

Even more worrying is that intensification of any treatment regimen (blood sugar, blood

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pressure or cholesterol) was associated with lower utility scores. Indeed, only treatment with aspirin was perceived as having a relatively minimal impact on the quality of life, with diet and exercise alone having no impact at all. It seems increasingly clear that although those caring for people with diabetes focus on short-term biomedical targets with a view to preventing long-term complications, people with diabetes think much more about their day-to-day lives and the inconvenience and social burden of the polypharmacy that is inflicted on them. Given what we know about low adherence levels of diabetes medications (including insulin), simplification of treatment regimens may improve outcomes. The recent debate about the polypill (Fahey et al, 2005) – a combination of a statin, thiazide diuretic, ACE inhibitor, β blocker, aspirin and folic acid – has focused more on risk reduction in low-risk populations than on patient acceptability and improved compliance.

Numerous other studies, and comparisons of patients' views with those of health professionals, demonstrate a much lower perception of future risk among people with diabetes, although the old concept of 'mild' diabetes (and not just among patients) does seem to be fading away in the light of a concerted professional campaign.

So, clearly, we have a long way to go. We need not just to start educating patients and populations about diabetes and its impact, but also to take real cognizance of patient preferences when deciding on therapeutic interventions. On a wider scene, quality-of-life concerns need to be recognised when planning initiatives to improve diabetes care. We must stop paying lip service to patient involvement and incorporate patient views at all levels of the decision-making process in diabetes care.

To find out how well these laudable aims are implemented in the day-to-day care of people with diabetes, the Year of Care project, co-sponsored by Diabetes UK, the DoH and the National Diabetes Support Team (Diabetes UK, 2007) is being rolled out to pilot sites this year. The overarching aim of the project is to improve the healthcare experience of adults with diabetes and support people to live a healthier life on a day-to-day basis. Investigators in the three pilot sites (Tower Hamlets, North Tyneside, and Calderdale and Kirklees) will try to find out if all the government rhetoric about

patient involvement can really be translated into improved patient satisfaction and better outcomes using the annual review as an opportunity to construct and review a care plan. This process is intended to be a joint and equal discussion between the patient and their diabetes team to decide upon individually tailored treatment options. Clearly, in an era of cost-constrained commissioning, this will have an impact, and managing the tide of patient expectation will be a challenge for both commissioners and providers of care.

Bernard Crede and Andrew Kenworthy, in their article starting on the next page, take us through how this, and the many other often conflicting political agendas, can be addressed. In Kensington and Chelsea, they are investing large sums of money in community diabetes services. In Bradford, where such services already exist, we are also investing huge sums in educating people newly diagnosed with diabetes. We need data urgently to support our decisions and demonstrate to professionals, planners and patients alike that such investment really does improve patient care. The Year of Care project should inform us all. ■

Page points

1. We need not just to start educating patients and populations about diabetes and its impact, but also to take real cognizance of patient preferences when deciding on therapeutic interventions.
2. Quality-of-life concerns need to be recognised when planning initiatives to improve diabetes care.
3. We need data urgently to support our decisions and demonstrate to professionals, planners and patients alike that investment really does improve patient care.

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