

not. Hence, of course, the scope for the export and import of ideas.

The government's reforms can be interpreted as an attempt to inject American style incentives to providers even while maintaining the traditional advantages of the NHS. Similarly, any American reforms, if they come, are likely to revolve around attempts to introduce a British style single payer—with the capacity to cap budgets—while yet maintaining the flexibility, variety, and choice of the existing system. Whether

either country can hope to have the best of every possible world remains to be seen.

RUDOLF KLEIN

Professor of Social Policy, Centre for the Analysis of Social Policy,
School of Social Sciences, University of Bath BA2 7AY

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“Brittle” diabetes

Usually settles down

The term brittle diabetes was coined by Woodyatt in the 1930s to describe a syndrome of “fragile” insulin dependent diabetes mellitus, characterised by swings from extremes of hyperglycaemia to hypoglycaemia for no obvious cause.¹ Tattersall broadened the definition to include patients whose lives were “constantly disrupted by episodes of hyperglycaemia or hypoglycaemia, whatever their cause.”² The diagnosis was much in vogue in the 1980s, when the use of home blood glucose monitoring and continuous subcutaneous insulin infusion encouraged attempts at physiological patterns of insulin replacement. Many patients in whom “brittleness” was diagnosed ended up at tertiary referral centres for investigation and treatment. Suggested causes included subcutaneous insulin degradation,³ impaired hyperaemic responses to insulin injection,⁴ and enhanced insulin clearance.⁵ Evidence for each was found in some patients but rarely in all.⁶ Long term infusions with intravenous⁷ or intraperitoneal⁸ insulin produced transient but rarely sustained improvements in metabolic control.⁹

Patients were almost exclusively young women negative for C peptide who tended to obesity and apparently required very large doses of insulin.¹⁰ The high prevalence of psychosocial difficulties and demonstrable manipulation of therapy suggested that the primary cause of the syndrome was psychosocial.¹¹ No controlled studies have looked at the prevalence of psychosocial difficulties in matched patients with non-brittle disease, although eating disorders, for example, are particularly common in those with brittle disease.¹²

Two recent studies have sought to determine the medium to long term outcome of patients with brittle diabetes. Tattersall and colleagues presented a case-control study of patients 12 years after they presented either with recurrent diabetic ketoacidosis or with severe hypoglycaemia.¹³ Their patients were atypical—half were men and only five had a mixed picture of swinging hypoglycaemia and hyperglycaemia. But they fitted well with Tattersall's own widely used definition of brittleness.

On p 285 Gill and Alberti report on the outcome in their original cohort of female patients with brittle disease.¹⁴ Both groups found that brittleness was not permanent, the Nottingham group more conclusively perhaps because of a longer follow up. The Nottingham study found a high incidence (80%) of psychosocial disorder. When two patients who died of renal disease early in the brittle phase of their disease were excluded, mortality was low, at least in people with recurrent diabetic ketoacidosis. One could speculate that the low mortality from diabetic ketoacidosis in these patients resulted from rapidly developing and often more readily reversible withdrawal of insulin rather than metabolic decompensation secondary to an intercurrent event. Apart

from one death among Gill and Alberti's patients (attributed to but not proved to be due to diabetic ketoacidosis), deaths occurred in patients prone to recurrent hypoglycaemia—and one at least of these was probably due to suicide. These findings are similar to those of an earlier, three year follow up study.¹⁴

“Pure” recurrent hypoglycaemia (Pickup's type B brittleness and Tattersall's “obsessive aglycosuria”) is probably a different disease, associated perhaps with loss of awareness of low glucose concentration. The syndrome of recurrent severe and asymptomatic hypoglycaemia, associated with delayed adrenergic and autonomic counterregulatory responses, has been recognised in patients receiving intensified insulin treatment¹⁵ and others.¹⁶ It may result from rather than be the initiating cause of recurrent hypoglycaemia.¹⁷ The vicious circle that results, however, makes it particularly dangerous for patients, like Tattersall's patients with obsessive aglycosuria, who are protected from disaster only by frequent accurate blood monitoring. It is becoming the “unstable diabetes” syndrome of the 1990s.

Longer term, the prevalence of microvascular complications seen in the follow up studies of brittleness is probably not dissimilar from that in the population with non-brittle diabetes. The evidence for this is particularly striking in the Tattersall study. It is interesting because patients with brittle disease are poorly controlled long term, both during their brittle phase and beyond.

Is there a physiological explanation for the syndrome of swinging between extremes of blood glucose concentrations? Vigorous counterregulatory responses to hypoglycaemia can produce intermediate or delayed insulin resistance (due to catecholamines¹⁸ or cortisol and growth hormone,¹⁹ respectively). In children counterregulatory responses are especially brisk and may start at higher blood glucose concentrations²⁰—add to this the growth hormone dependent insulin resistance of puberty, and the adolescent is well set up for severe post-hypoglycaemic hyperglycaemia.²¹ Adolescents are often the most vulnerable to metabolic instability, with a close correlation between onset of brittle disease and the menarche.¹⁰ Patients with poorly controlled diabetes also have exaggerated counterregulatory responses and relative insulin resistance and may be similarly vulnerable. Brittle disease, once it has started, may thus be self perpetuating.

Meanwhile, the commonest cause of posthypoglycaemic hyperglycaemia remains excessive oral intake, and this may produce particular problems in young patients with poorly controlled disease, who become severely symptomatic at relatively high glucose concentrations. One form of brittleness can best be treated by carefully reorganising therapeutic regimens.²² Should such patients be labelled as having brittle

disease? Even if we accept that then the psychosocial stresses of adolescence contribute at least as much as physiology to poor control.

Brittle became a convenient word for parents, nurses, and doctors struggling to cope with difficult metabolic control in their charges. Brittle diabetes does exist—in the sense that some young (and some not so young) patients with poorly controlled diabetes do experience very unstable glycaemic control. And specific abnormalities—for example, of insulin absorption—have been found.⁷ But the term has become inextricably associated with cases of manipulative behaviour and carries pejorative overtones. Our increased understanding of the metabolic causes of diabetic instability and the contribution of psychological stress to erratic glycaemic control gives us new, more specific, diagnostic labels.

The follow up studies lead to the conclusion that brittle diabetes may be self limiting and not intrinsically different from non-brittle diabetes in the long term. The main risk to life is recurrent hypoglycaemia, which may be a separate syndrome. Any psychosocial difficulties need treatment. Deciding how to use expensive and potentially dangerous treatments is not easy. Indeed, the effect of the intensive regimens used for brittleness has not been examined—outcome might have been different without them. Regardless of their label, patients with unstable diabetes need expert multidisciplinary care.

STEPHANIE A AMIEL

Senior Lecturer, Unit for Metabolic Medical Medicine,
Division of Medicine, United Medical and Dental Schools,
Guy's Hospital, London SE1 9RT.

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What do patients want?

Someone who will hear their questions

Patients consult doctors because they want help with their illnesses. Writing in 1935, Brackenbury interpreted this as meaning that patients wanted clinical competence; unable to judge this for themselves, they had to rely on the professional integrity of doctors.¹ For many years doctors have regarded patients as relatively passive, but this has begun to change.

Researchers drawn from both medicine and the social sciences first noticed the change in the years after the second world war when they began to inquire beyond the presenting symptom to the patient's view of health, illness, and medical care.² The finding that most people who became ill chose not to visit their doctor³ and reports of patients' low rates of adherence to medical advice and treatment⁴ undermined the assumption that illness was taken to the doctor for clinical help. Patients seemingly wanted something more. Surveys of patients' views identified one recurrent complaint: doctors rarely provided sufficient information about their medical problems,^{5,6} and, for a time, competent clinical care, courtesy, and adequate information summed up what patients wanted.⁷

Over the past decade, however, what patients want has undergone a fundamental reappraisal. The cornerstone of professional practice has always been that, though patients might know what they wanted, doctors (through their specialised knowledge) knew what they needed. Emphasis on good clinical care and information giving still reflects medical definitions of what is needed; the major shift has been an increasing recognition that patients' wants are not capricious whims but needs in themselves. Explanation and understanding, as well as emotional support, have now been added to medical treatment and information as the main things that

patients want from their doctors.⁸

Intensive studies of patients' perceptions of illness have discovered that patients hold elaborate and often sophisticated theories of their own illness.⁹ In essence patients seem to need answers to three basic questions about their illness: "Why me?" "Why now?" and "Why this (particular illness)?"¹⁰ They seek information that helps to answer these questions in a form that makes sense to them; indeed, some visits to the doctor may be made expressly for this purpose.

Recent work on the ways patients cope has confirmed the importance of widely differing desires for information. Patients have been divided into those who search for and demand more information about their problem ("monitors") and those who deliberately avoid information, especially that which might have negative connotations ("blunters").¹¹ Thus patients who complain about the lack of information may paradoxically be the best informed.

At least some of this reassessment of what patients want can be explained by the growth of consumerism and the belief that the rights of the consumer are sovereign. This movement is evident in the recent NHS reforms, which have created—at least as part of the rhetoric—more of a market place for health care, in which consumers' wishes can be better accommodated. Further evidence for the greater attention given to what patients want is the growth of routine surveys of patients' satisfaction and more formal studies of patients' views of medical care (p 289).¹²

What are the limits of this new consumerist medicine? Patients need protection from the dangers inherent in much medical investigation, diagnosis, and treatment and for the