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Brittle diabetes

Many patients with insulin dependent diabetes spend their lives walking a tightrope between extremes of high and low blood sugar concentrations. Most have abnormally variable values much of the time but stay out of major trouble with an average of only one hypoglycaemic coma every six years and one admission with ketoacidosis every 10. An unlucky or improvident few have their lives and those of their families disrupted by repeated episodes of hypoglycaemia or ketoacidosis. The scale of their instability may be daunting; one of our middle aged patients had 136 hypoglycaemic comas in six years,[1] while a 13 year old girl reported by Pickup *et al* had 50 admissions with ketoacidosis in 18 months.[2] Laymen would regard these as obvious examples of brittle diabetes, but some diabetologists might not agree.

The crux of the matter is whether the epithet "brittle" should be used where the cause of the instability is known. Woodyatt called patients brittle if they were subject to frequent and unpredictable fluctuations between hyperglycaemia and insulin reactions—provided that known causes of instability had been excluded.[3] Molnar and colleagues at the Mayo Clinic defined brittleness as extreme variability in the blood glucose response to consistent treatment in metabolic ward conditions thus excluding patients who were unstable in the community but stable in hospital.[4] Instability of blood glucose may be quantified but this expands the definition of brittleness to patients whose only problem is a degree of variability of blood glucose which affronts their doctors.[4,5] Insistence on excluding known causes of instability assumes diagnostic omniscience and is unhelpful if it leads to the advice that "ordinarily no specific cause for true brittleness can be found."[6] I and my colleagues have argued that diagnostically it is more useful to reserve the term brittle diabetes for that small but conspicuous, exasperating, and expensive minority of patients whose lives are constantly disrupted by hypoglycaemia or hyperglycaemia whatever the cause.[7,8] In practice the problem is usually either recurrent hypoglycaemia or recurrent ketoacidosis and only rarely a combination.

No systematic analysis of the causes of recurrent hypoglycaemia has ever been published, and it is debatable how frequent it must be to be regarded as pathological. Much depends on what targets are set and what tools the patient is given. In the 1930s hypoglycaemia was regarded as an inevitable effect of trying to keep the urine free of sugar by multiple injections of soluble insulin; those who did best in terms of avoiding complications were those who had at least one coma each year.[9] Better insulin regimens and home blood glucose monitoring have made it easier for patients to achieve nearly normal concentrations of blood sugar without such alarming side effects, though some patients believe that the best way to avoid complications is to sail as close to the wind as possible keeping their blood sugar on the verge of hypoglycaemia most of the time. In our experience patients with recurrent hypoglycaemia may be of either sex and heterogeneous in age and duration of their disease.[10]

Much recent interest has been shown in patients who lack warning symptoms of hypoglycaemia or an adequate counter-regulatory hormonal response or both. Those who lack secretion of both catecholamine and glucagon are defenceless against hypoglycaemia since they get no warning and cannot increase glucose production to compensate for continuing hyperinsulinaemia.[11,12] Anti-insulin antibodies may compound the problem by maintaining abnormally high serum concentrations of insulin.[11] The only solution for such people may be to set less stringent blood glucose targets. Lack of counter-regulation is not the only cause of recurrent hypoglycaemia; some patients have normal hormonal responses.[13] Other possibilities[7,8] include increased insulin sensitivity, an unrecognised low renal threshold for glucose, unsatisfactory insulin regimens, overtreatment with insulin, obsessional overcontrol, and deliberate manipulation or fecklessness.

Most diabetologists are confident when diagnosing and treating recurrent hypoglycaemia but may be uncomfortable with patients repeatedly admitted in ketoacidosis, whom they are only too happy to offload. In the past five years one American and two English groups have collected series of patients with "idiopathic" brittle diabetes by tertiary referral.[14-16] These patients are usually overweight adolescent girls who take large doses of insulin and have enormous bundles of case notes. Early admissions with ketoacidosis may be attributed to intercurrent illness, but in time more subtle explanations are sought, such as erratic insulin absorption,[2] abnormalities of subcutaneous blood flow,[17,18] or other causes of insulin resistance. These girls are often emotionally disturbed, frustrated, and depressed, and "roam from doctor to doctor in search of one who knows the whole answer,"[18] but opinion is sharply divided whether the emotional disturbance is the cause or effect of their diabetic instability. Three theories are current. Firstly, the liability

might be organic and a consequence of inappropriate metabolic responses, some known and others to be discovered.[14 15] Secondly, emotional stress might be the primary cause with diabetic control being disrupted through physiological mechanisms.[19] Thirdly, emotional stress might be the primary cause with diabetic control being disrupted through inappropriate behaviour, usually to extricate the patient from an otherwise insoluble dilemma in her personal life.[20]

Each theory may be correct in specific cases, though the advocates often give the impression that their pet theory is a universal truth. Opinion and anecdote have often outweighed the evidence; proponents of the organic theory point out that their patients have been examined psychiatrically and given a clean bill of mental health (in other words, that they conform to the original definition in that known causes of instability have been excluded). Baker and colleagues,[19 21] who support the second theory, have successfully treated apparently typical patients, mainly children, with family therapy. Supporters of the third theory can adduce many anecdotal case histories and small series showing that diabetic patients may sabotage their treatment for secondary gain; for example, Loughlin and Mosenthal found that a third of children with recurrent ketoacidosis came from broken homes and that many freely admitted that they preferred hospital to home.[22] Rosen and Lidz were able to establish that in all 12 patients with recurrent ketoacidosis the condition had been deliberately induced; motivation varied and the same patients disrupted their diabetes for different reasons on different occasions.[23] Similar cases were documented by Stearns, who emphasised that such potentially self destructive behaviour might represent a need for self punishment, attention seeking, or the urge to punish others.[24]

This complex topic has been partially clarified by the recent work of Schade *et al*, who systematically investigated 30 patients using a diagnostic algorithm, the central feature of which is to measure the hypoglycaemic response to a standard dose of insulin both subcutaneously and intravenously.[16 25] The authors did this test whether or not the referral letter stated (as it usually did) that the patient had been shown to be insulin resistant and that interference with treatment could be excluded. Twenty eight of 30 patients were normally sensitive to insulin, and the eventual explanation of brittleness was some act or omission by the patient which had been deliberately or involuntarily concealed from previous investigators. That a high proportion of patients will eventually turn out to have factitious problems is supported by the latest report of the Newcastle group, of whose 33 tertiary referrals 14 were either "psychological" or due to therapeutic error.[26] Moreover, of the remaining 19 girls with "idiopathic" brittleness, half are known to have interfered with their treatment "often to secure or maintain their hospital admission thereby avoiding intolerable domestic circumstances."

Gill *et al* have now put forward a unified theory which proposes that these girls begin by interfering with their treatment for emotional reasons but that escalation of insulin doses, continued cheating, and repeated admissions complete a vicious circle leading to chronic hyperglycaemic instability from which the patient cannot escape.[26] The linchpin of this theory is the proposition that many patients have had "well documented episodes of extreme insulin resistance on witnessed occasions when they were seriously ill and bed bound, *and could not possibly be interfering with treatment*" (my italics). Certainly extreme insulin resistance may occur and be due to organic factors[27]—but it is much rarer than factitious insulin resistance. I believe that diabetologists commonly miss factitious disease, partly because we have been led to believe in a condition called "idiopathic brittle diabetes," partly from a deep seated reluctance to believe that patients would deceive us wilfully, partly from our great fear of missing organic disease, and, finally, because we have a stereotyped picture of the sort of patient we would expect to "cheat," which often excludes those considered to be "normal and nice."[16 28]

The discovery that a patient's brittle diabetes is factitious causes acute discomfort in the unit with the patient being branded as a liar, trickster, or swindler. This is understandable but unhelpful to the patient. More comprehensive psychiatric evaluation will generally show that the patient has been driven to such potentially self destructive behaviour by intolerable family or personal pressures. What is important is that the correct diagnosis has at last been made and that appropriate treatment can now be attempted. Psychiatric assessment and back up are necessary, but the diabetologist must remain the central figure since splitting the physical and emotional care tends to create confusion and offers opportunities for manipulation and playing one doctor off against another. No neat solution may be possible; treatment may simply be a question of sharing the patient's frustrations and anxieties. Everyone must be made aware that treatment is likely to be prolonged and that the responsibility for a successful outcome does not lie with the doctor alone—the patient, family, and friends must be prepared to cooperate.

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Ethics and politics

The dividing line between ethical and political analysis has long been blurred: sometimes the two merge, sometimes they are in conflict. Socrates encouraged the young men of Athens to think critically about ethical issues. Later it was found "politically expedient" to put him to death for his troubles. Today politicians prefer to put moral philosophers to death by trying to ignore them.

The Warnock committee spent years deliberating over the moral problems of new methods of reproduction only for Enoch Powell to disregard its report and use parliament to promote his personal repugnance of those methods. No major political party has established policies on abortion, euthanasia, the care of handicapped neonates, or any other major medicomoral issue, preferring instead to leave these matters to the individual consciences of members of parliament; regrettably individual conscience may in some cases be tantamount to individual ignorance. The government has not been restrained from imposing a limited drug list by any consideration of the way in which such a list interferes with a doctor's moral duty to provide the best possible service to each individual patient.

Occasionally the conflict is more blatant. In Athens last January there was a research workshop on ethical problems in preventive medicine sponsored jointly by the North Atlantic Treaty Organisation and the European Economic Community. After the meeting contributors met to discuss publication of the proceedings and were told, by the representative from the European Economic Community, that there could be no mention of alcohol as a problem because the community had several wine producing member states.

How can politicians be encouraged to take a more informed interest in the ethical problems of medical practice? The simple answer is to provide them with accurate information. As each new problem develops members of parliament tend to be deluged in mail from whichever lobby believes that its interests are being challenged. The BMA can help to counter partisan views, but the influence of its central ethical committee is, perhaps, less than it might be because the committee's members are judged to be primarily medico-politicians—responsible to an elected council and representative body—rather than experts in medical ethics.

One organisation that is trying to provide accurate information on medicomoral problems for politicians and the general public as well as doctors is the Institute of Medical Ethics. The institute has expanded the work of the Society for the Study of Medical Ethics and its associated medical groups in the university teaching hospitals (begun in 1963), and membership is now open to the public as well as to those professionally interested. Members receive a monthly bulletin giving information on a wide range of topics in medical ethics and recording relevant official statements. The institute also runs courses for medical and nursing teachers and organises working parties to examine particular problems in medical ethics. The next report—the ethics of clinical research on children—will appear in the autumn.

Whether the Institute of Medical Ethics can satisfy the increasing demand for public discussion and participation in decision making will largely be determined by the amount of financial support that it can attract. Professor Ian Kennedy and Dr John Dawson, head of the BMA division responsible for medical ethics, have both suggested that there should be a British equivalent of the United States President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research to advise the government. Such a commission cannot be independent, however, so long as it depends on the government for funds: this was well illustrated by the President's Commission itself, which ceased to exist in March 1983 when United States government funds were withdrawn.

The Institute of Medical Ethics and its predecessors have never depended on one main source of funds and have thus maintained their reputation for independence and neutrality. The institute does not promote any one sectarian approach to particular problems but tries to provide information about differing views so that people are encouraged to make up their own minds. With adequate support it could make a major contribution to the education of politicians, and the public, and thus help to clarify the dividing line between ethics and politics in medicine.

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Services for people with head injury

Eight patients with head injuries were found to have been in acute wards of a London teaching hospital for up to two and a half years. Six of them were said to have potential for rehabilitation but apparently had nowhere else to go. They were among 101 patients with disabilities discovered in a survey of 660 "acute" beds reported by C J Goodwill to a recent meeting of the Society for Research in Rehabilitation. Even those who do have intensive rehabilitation, however, may not do well.[1] In A D Tyerman's follow up study—eight months after discharge and on average 20 months after injury—29 of 57 people with head injuries were staying at home and inactive. Since discharge they had tended to become more distressed and their expectations had fallen. Indeed, for many such people the realisation that they will never recover their old selves and their old functions comes at a time when no help is at hand—a finding that underlines the need both for very long term sources of help and for an emphasis on helping patients with head injuries to an acceptance of their new self at an earlier stage by counselling and psychological approaches.

That the prospects are not all bleak, however, became apparent at the Medical Disability Society's symposium on better services for head injury that preceded the other meeting. C D Evans reported that no one in his series who had been unconscious for over three weeks had worked again, and all those who had been in a coma for more than three months were institutionalised; but, by contrast, all those who had been in a coma for no more than 10 days did have work when followed up five years after their injury; in all, 53 of the 96 who had been unconscious for more than an