PostScript

VIDEO REVIEW

Chronic fatigue syndrome: a clinical view

Audiovisual Department, Southampton University, 2003.

This is an excellent video which I would highly recommend to anyone who deals with young people and adults with chronic fatigue syndrome (CFS): not only will health professionals find it a useful resource but teachers and families too. The treatment approach of the team in Southampton is presented in a clear and coherent way and the choice of articulate patients and parents to explain the illness and its impact on their lives is particularly helpful. In a logical way the video goes through the causes of CFS and making the diagnosis. A large section of the video is concerned with the treatment programme, stressing the importance of team work and engaging with the family to ensure that they are "on board" with the treatment. Drug usage and symptom relief are discussed, as are the use of complementary therapies. The focus of the treatment in Southampton is graded rehabilitation and cognitive behaviour therapy, and I believe that some patient groups will not rest easy with some of the aspects of care advocated by the Southampton group. At the end of the video is a section on prognosis and discharge.

Some aspect of the video I found disappointing. For example, it suggests that 2% of young people are affected by CFS and that the sex distribution is equal, but the reason for this statement is not discussed and does not accord with published data. The recent RCPCH/RCGP community based survey suggests a prevalence of 0.066%, two thirds of whom were girls. The consequence of this was to make me feel that if they had got this wrong, what else was wrong in the video? The video tended to avoid some of the contentious aspects of CFS management with which many paediatricians have most difficulty; although education is discussed, there is no mention of the pros and cons of home tuition. Rightly the video stresses the importance of engaging with the whole family, but there is no mention of what to do when the relationship between the family and the therapeutic team breaks down. The role of social services and child protection issues are also not dealt with. It would have been very helpful to have some advice on the management of the very severely affected bed ridden individual; as it is those patients who are the most taxing in terms of treatment.

Technically, the video is well produced with clear sound and pictures. There are not any glaring continuity problems, though the posterisation of some of the images was a little bit annoying. I wonder in 2003 whether production in DVD format would have been appropriate, with chapter headings for each section, allowing the viewer to jump to their areas of interest.

Despite my reservations above, this is an excellent resource which would be of value in

any departmental library. It should also find a place in the school health service as an information resource for school nurses and teachers.

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LETTERS

Community growth monitoring in practice

The aim of routine growth monitoring (GM) of school age children is to identify children with the so-called "silent" conditions. These include growth hormone deficiency, hypothyroidism, and Turner's syndrome. Using the UK 1990 nine centile growth charts it has been recommended that all children with heights less than the 0.4th centile should be referred to growth clinics for further assessment.¹ We evaluated a district GM programme fulfilling this criterion, to assess its outcome.

A total of 89.6% (3465/3864) of children in the 1999-2000 reception class (mean age 4.83 years) had their height and weight measured by school health nurses. The mean height of all the children was 108 cm with a mean height standard deviation score of 0.052; 18/3465 children (0.5%) had heights less than the 0.4th centile. Fourteen of these children have now been assessed. Table 1 shows their diagnoses.

In our programme, 50% (7/14) of children with heights less than the 0.4th centile in whom a diagnosis has been made had an organic disorder. This is a better yield than either the Wessex growth study² (which used height <3rd centile as criteria for further assessment) or the Oxford Growth study³ (which used height <2SD). The percentage of children with heights below the "cut off" that had an organic disorder in those studies were 18% and 43% respectively.

Our programme detected two children with idiopathic growth hormone deficiency (IGHD). This is more than would be expected given that the prevalence of IGHD is 1:4018.⁴ There were no children with Turner's syndrome in our cohort. This may be because of our sample size as the prevalence of Turner's syndrome is 1:2500 female live births.⁴ It could however be that using the 0.4th centile as referral criterion is too strict as a proportion of children with Turner's syndrome will

be taller than the 0.4th centile at this age. In the Wessex Growth study, two children identified with "silent disease" had heights above the 0.4th centile.⁵

In our programme, although a new significant diagnosis was made in 0.1% (4/3465) of the cohort, we remain concerned that the 0.4th centile "cut off" may be too strict.

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The collusion of anonymity in paediatrics

One of the thankless, if necessary tasks of the NHS general practitioner is to sort and summarise incoming GP records of patients new to the practice.

While carrying out this noble duty, we looked at the records of an 11 year old patient with cerebral palsy who, in his brief life had seen 15 consultants, one research fellow, one clinical assistant, one senior medical officer, one clinical fellow, one principal health physician, and six registrars on 62 different occasions in 10 different specialties. At one point the patient was under the care of two

Table 1 Diagnoses of children with heights less than the 0.4th centile

	Newly identified by programme	Diagnosed prior to programme
Autoimmune hypothyroidism	1	0
Idiopathic growth hormone deficiency	2	0
Intrauterine growth retardation	1 (with major psychosocial problems)	1
Batter's syndrome	0	1
Cystic fibrosis	0	1
Familial short stature	5	2
Total	9	5

community paediatricians simultaneously. In an orthopaedic clinic, the patient saw six differently named doctors on six clinic visits. Along with the medical appointments, there were up to seven clinic visits a week for other clinicians: physiotherapists, speech and language therapy, health visitor, psychology, occupational therapy, wheelchair assessment, and other.

This case illustrates a number of important issues for consideration by specialists, who may be tempted to refer:

- Dilution of responsibility—vital decisions are made without anyone feeling fully responsible for them; the “collusion of anonymity” described by Balint.¹
- Increased burden of care on the parents of a disabled child; the sheer physical and time effort required in getting a disabled child to a clinic and then waiting for the specialist can be imagined.
- The potential for confusion of opinions between specialists in the same field.
- In this case, the lack of any obvious medical benefit from many of the multiple cross-referrals.

We hope that paediatricians will consider carefully the need for cross-referral and the need for a single point of contact for the parent of the disabled child.

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The Seville effect

For some, football is more a religion than a sport. This can impact on families in multiple ways. One such quasi-religious event was the UEFA Cup Final between Glasgow Celtic and Porto (21 May 2003). An estimated 85 000 Celtic supporters converged on Seville for the UEFA Cup Final.

While doing two paediatric clinics on the day of the Cup Final I noted that the “did not attend” (DNA) rate at these clinics was well above normal, being 58.4% and 58%.

My hypothesis was that this quasi-religious event was being put before children’s health, shown by their failure to attend paediatric clinics. I decided to look at the DNA rates at Glasgow’s tertiary paediatric hospital, Yorkhill Hospital and the paediatric department of a large District General Hospital Trust, Ayrshire and Arran NHS Trust. The DNA rates at identical clinics the week before and after the Cup Final were analysed to allow appropriate comparison. The mean DNA rate was 14.58% on the day of the UEFA Cup Final, 17.38% on 14 May and 19.06% on 28 May. This in fact shows a trend towards attendance on the day of the UEFA Cup Final but this did not reach significance ($p = 0.3$). Reassuringly this refutes the hypothesis that Glaswegians will put football before their child’s health.

The breakdown of the subspecialty DNA rates had some interesting results. The

Table 1 Number of non-attenders in three subspecialties

Department	14 May	21 May	28 May
General paediatric clinic	4/36 (11.1%)	16/50 (32%)	11/41 (26.8%)
Nephrology clinic	7/43 (16.3%)	8/31 (25.8%)	1/16 (6.3%)
Respiratory clinic	1/13 (7.7%)	2/6 (33.3%)	1/12 (8.3%)
Total	12/92 (13%)	26/87 (29.9%)	13/69 (18.8%)

haematology clinics, for example, had the lowest DNA rates, with an average of 5.9% (5/54 and 1/42 on 14 and 28 May respectively) not attending on the dates before and after the Cup Final. The DNA rate on the day of the Cup Final was 2/39 (5.1%). Other specialties including general medical paediatric, nephrology, and respiratory clinics showed a very different picture (table 1). When comparing the average DNA rate at these clinics with that on 21 May, there was a significant increase in failure to attend ($p = 0.019\%$).

From this we can say that despite the huge exodus of football followers in the West of Scotland that occurred on the day of the UEFA Cup Final, the attendance rate at paediatric clinics in the West of Scotland was better on the day of the Cup than normal. This is very reassuring in this football frenzied area. However, it may be said that certain paediatric illnesses were treated with less importance.

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Nephrotic syndrome relapse: need for a better evidence based definition

Despite the occurrence of relapses, steroid sensitive nephrotic syndrome (SSNS) has a good long term prognosis. As it often heralds a clinical relapse, significant proteinuria (+++ or more on albustix) for ≥ 3 consecutive days (simplified as P3D in this letter) defines a relapse, resulting in steroid therapy before the onset of oedema. Proteinuria may be triggered by viral infections¹ and does not always develop into a relapse.²

We have observed 24 consecutive episodes of asymptomatic P3D, without oedema, occurring during a viral illness, in four children (two boys, two girls, age range 2–5 years) known to have SSNS. In eight of these episodes, the families refused to rush with steroid therapy; serum albumin level remained >30 g/l in the three where measured, and the proteinuria resolved between 5 and 10 days. Sixteen other episodes occurred in three children, who were treated as relapses; all three were later labelled as frequent relapsers and started on long term steroid therapy. None required renal biopsy. One child required cyclophosphamide and two required levamisole therapy; a rash occurred in one. None could be vaccinated against varicella while on steroid therapy; all required varicella zoster immunoglobulin injections after contact with chickenpox,

and one child developed varicella while on steroids and required acyclovir therapy.

In this series, 33% (exact binomial 95% confidence intervals 15% to 55%) of the P3D episodes were not relapses: there was no hypoalbuminaemia or oedema, and they resolved spontaneously within 5–10 days. We cannot ascertain how many of the remaining episodes were genuine relapses, as some may well have also resolved spontaneously after a few days. Although not blinded or controlled, this observational study challenges the current definition of relapse by the sole presence of P3D, confirming studies where up to one third of such episodes did not develop into a relapse and where waiting 10 days before starting therapy did not influence the course.² Defining a relapse only by P3D may therefore lead to unnecessarily treating 15–55% of affected children, and may cumulatively lead to over-diagnosing frequent relapses, resulting in unnecessary renal biopsy, prolonged steroid courses, and therapy with cyclophosphamide, cyclosporin, and levamisole, with their potential side effects.

As the natural history of isolated proteinuria in children with SSNS remains largely unknown, there is a clear and urgent need for larger prospective controlled studies in order to define relapses more accurately.

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CORRECTION

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Molyneux E, Forsyth H, Tembo M, et al. The effect of HIV infection on paediatric bacterial meningitis in Blantyre, Malawi (*Arch Dis Child* 2003;**88**:1112–18). The authors would like to apologise for an error in the results section of the abstract of this paper. The sentence “the number of survivors in each group was similar” should have been omitted prior to publication.