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, but it is essential that our patients with CFS 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, but it is essential that our patients with CFS...
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 clinics: 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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Reference


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 subspeciality DNA rates had some interesting results. The 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 infections and does not always develop into a relapse.¹

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 relapers and started on long term steroid therapy. None required renal biopsy. One child required cyclophosphamide and two required leva_misole 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 hypoa obeseaemia 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 leva_misole, 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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References


Molyneux E, Forsyth H, Tembo M, et al. The effect of HIV infection on paediatric bacterial meningitis in Blantyre, Malawi (Arch Dis Child 2003;88:112-18). 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.

Table 1: Number of non-attenders in three subspecialties

<table>
<thead>
<tr>
<th>Department</th>
<th>14 May</th>
<th>21 May</th>
<th>28 May</th>
</tr>
</thead>
<tbody>
<tr>
<td>General paediatric clinic</td>
<td>4/36 (11.1%)</td>
<td>16/50 (32%)</td>
<td>11/41 (26.8%)</td>
</tr>
<tr>
<td>Nephrology</td>
<td>7/43 (16.3%)</td>
<td>8/31 (25.8%)</td>
<td>1/16 (6.3%)</td>
</tr>
<tr>
<td>Respiratory clinic</td>
<td>1/13 (7.7%)</td>
<td>2/6 (33.3%)</td>
<td>1/12 (8.3%)</td>
</tr>
<tr>
<td>Total</td>
<td>12/92 (13%)</td>
<td>26/87 (29%)</td>
<td>13/69 (18.8%)</td>
</tr>
</tbody>
</table>

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