Sickle cell disease pain in London and the Caribbean

S Chakravorty, K Newell, J Ramchandani, K Qureshi, R Ibrahim, B Datta, P T Telfer


Pain is a common symptom in children with sickle cell disease (SCD). Hospital admissions for treating pain are frequent in parts of the UK where SCD is prevalent.1,2 In Jamaica, pain is often managed at home or in a day care setting and analgesic use is probably less.3 The question is often asked whether sickle cell pain is less frequent and severe in Caribbean children or whether they have developed effective coping skills to reduce the impact of pain on daily activities.4 Observations of better school attendance and less frequent visits to hospital when in pain would be consistent with the latter.

There have been previous reports using pain diaries in SCD.5 In order to compare pain experiences, we designed a simple diary, and evaluated it in a simultaneous study of children in inner city London and on a Caribbean island.

METHODS

Inclusion criteria were a diagnosis of homozygous SCD, and age 5–15 (up to 24 in St Vincent). Exclusion criteria were chronic transfusion or hydroxyurea therapy. Sixty patients at the Royal London Hospital were selected randomly. In St Vincent all identifiable children were enrolled. Children (with parents help if aged 5–7) were asked to complete diary days over a four week period. The diary was designed in a simple, “child friendly” format with one A4 page per day. Parents were contacted at the end of two weeks to ensure compliance and address problems, and questioned at the end of the study. Hospital attendance data were checked with hospital records. Pain data were compared using non-parametric statistical tests. Ethical approval was granted by the East London and City Health Authority Research Ethics Committee and by the Kingstown Hospital Board of Governors.

RESULTS

Of the 60 children in London, 14 declined to participate, 17 were not contactable, six did not collect the diaries, and six did not return the diaries at the end of the study, leaving a total of 22 patients analysable. In St Vincent, 31 children were recruited. Three were found to have other diagnoses, four filled the diaries incorrectly, leaving a total of 24 analysable. The mean age at study entry was 10.5 (SD 3.41) years in London and 12.3 (SD 5.39) in St Vincent. These differences were not statistically significant. There were 54% males in both groups.

A total of 1273 diary days were analysed. London children reported 243 (39%) of 619 days with pain compared with 153 (23%) of 654 days in St Vincent. London children were twice as likely to suffer a painful day (odds ratio 2.12, 95% CI 1.65 to 2.72, p < 0.001, fig 1). There was a significantly larger numbers of episodes of severe pain (maximal pain scores) among St Vincent patients compared to those in the London group (odds ratio 2.77, 95% CI 1.68 to 4.55, $\chi^2$ 18.6, p < 0.001).

St Vincent children suffered significantly more pain in the mornings. Pain occurred most frequently in the abdomen in both groups. There was a similar disruption of daily activities in the two groups (see table 1). Three London children visited casualty for pain relief during the study. All were admitted for intravenous morphine. In St Vincent four children visited casualty on six occasions. Two children were admitted to the ward for further treatment.

Painkillers were used on significantly more pain days by the London children: paracetamol 82% v 58%, aspirin-like painkillers 14% v 1%, outpatient opioids 64% v 0%. Other types of pain management in London included “Vicks” and “rest”; in St Vincent, “penicillin”, “warm milk”, and “rest”.

DISCUSSION

This study has shown that a simple diary can provide useful clinical information on sickle cell pain, and the majority of children are able to fill in the diary as instructed with parental help in some cases. Most of the pain was managed at home without hospital contact. London children experienced more days with pain, but severity was slightly greater in St Vincent.

The significantly greater use of analgesics drugs in London reflects the more aggressive therapeutic approach to pain in the UK and also the relative lack of resources in St Vincent. Contrary to our expectations, hospital attendances were equally frequent between the two sites, and children missed school equally frequently when in pain. It seems unlikely that children in St Vincent have developed more effective pain coping strategies, and pain appears to have a similarly disruptive effect on daily life in the two groups.

The study suggests that resources for managing sickle cell pain should be directed towards helping the child and the carers.

Table 1 How pain affected daily activities (% of pain days)

<table>
<thead>
<tr>
<th></th>
<th>London (%)</th>
<th>St Vincent (%)</th>
</tr>
</thead>
<tbody>
<tr>
<td>Absent from school/work</td>
<td>38</td>
<td>41</td>
</tr>
<tr>
<td>Unable to play</td>
<td>27</td>
<td>18</td>
</tr>
<tr>
<td>Stayed in bed</td>
<td>12</td>
<td>21</td>
</tr>
<tr>
<td>Visited casualty</td>
<td>2</td>
<td>4</td>
</tr>
<tr>
<td>Stayed in hospital</td>
<td>7</td>
<td>4</td>
</tr>
</tbody>
</table>

Figure 1 Frequency of pain days.
as they cope with the pain at home. This would include appropriate use of oral analgesia, home visits by sickle nurse specialists, alternative therapies, and help in the development of psychological coping mechanisms.

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REFERENCES

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