**Supra-regional referral patterns of childhood cancer patients**

The care of the overwhelming majority of children with cancer in the UK is organised through the 19 paediatric oncology principal treatment centres (PTCs), with treatment given at the regional PTC or at a local shared care centre. For certain types of childhood cancer, however, some highly specialised aspects of treatment are managed at a much smaller number of supra-regional centres. This report presents data from the National Registry of Childhood Tumours (NRCT) on patterns of referral to supra-regional centres for three diagnostic categories: retinoblastoma, liver tumours, and bone tumours. Patients are clarified by place of residence at diagnosis. Within England, data are presented for Strategic Health Authorities (SHAs). These are coterminous with Government Office Regions (GORs) except that the South East GOR comprises two SHAs, South-East Coast and South Central, which have had different referral patterns. Information on supra-regional referral is derived from NRCT records (mainly registrations from PTCs) and from linkage of the NRCT to Hospital Episode Statistics (HES).

Retinoblastoma referral 2002-2009

A national referral policy for retinoblastoma in the UK was introduced in the UK in 2002. The National Specialised Commissioning Group (NSCG) has designated two ophthalmological treatment centres for retinoblastoma, one in London (including at different times Moorfields, St Bartholomew’s, Royal London and Great Ormond Street hospitals) and one in Birmingham. Many patients are cared for jointly by a retinoblastoma and a regional paediatric oncology PTC. Table 1 shows referral of retinoblastoma patients during 2002-2009. Similar numbers of children were referred to each of the two main centres in 2002-03 but 60% of UK children diagnosed in 2004-09 were referred to Birmingham. Region of residence within England was classified by Strategic Health Authority. The numbers in Table 1 do not represent the total case load at either of the main centres since both London and, to a lesser extent, Birmingham also take patients from outside the UK. In particular, London provides a retinoblastoma service for Malta and Birmingham performs a similar function for Cyprus. Children from London and South East Coast SHAs were referred exclusively to London and all West Midlands children were referred to Birmingham. Otherwise there was little consistency in geographical patterns of referral. Patterns changed over time for some regions. Between 2002-05 and 2006-09 the proportion of children referred to Birmingham increased from 67% to 92% in the North West and from 48% to 89% in Yorkshire and Humber. A few children from Yorkshire and Humber were treated entirely at Sheffield until 2003. From 2006 some children from Northern Ireland were referred to Dublin. There was a previous family history of retinoblastoma in 12% of children, with equal numbers referred to each of the main centres.

Liver cancer referral 1998-2007

Nearly all UK children with liver cancer are under the care of paediatric oncologists at regional PTCs. A small proportion of children with liver cancer receive a liver transplant. NSCG has designated three paediatric liver disease centres where all liver transplants for children in the UK are performed. These centres are at Birmingham, Leeds and London (King’s College Hospital). The data presented here are based on records of all children in the UK with hepatoblastoma, carcinoma, sarcoma, germ-cell tumour or unspecified malignant tumour of the liver. Lymphomas, neuroblastoma and non-malignant tumours are excluded.

During 1998-2007 there were 213 registrations for liver cancer in UK children, comprising 147 cases of hepatoblastoma, 32 carcinoma, 5 malignant haemangioendothelioma or angiosarcoma, 25 other sarcomas, 2 germ-cell tumours and 2 unspecified tumours. Table 2 shows numbers of children with liver cancer who received a liver transplant at one of the three centres. Overall, 14% had a transplant, with no change between 1998-2002 and 2003-2007. Ten children were transplanted at Birmingham, four at Leeds and 16 at London. In two cases the transplant followed tumour recurrence, and one further child had two transplants. The proportion receiving a transplant was higher for hepatoblastoma (18%) than for carcinomas (6%) or other tumour types (3%). South West England had the highest proportion of children receiving a transplant (29%).

Bone tumour referral 1998-2007

Specialist treatment for patients with bone tumours in England and Wales, especially orthopaedic surgery, is provided by five NSCG-designated bone tumour services in London, Birmingham, Newcastle, Oxford and Oswestry. In many cases, non-surgical aspects of the care of children with bone tumours are managed by regional paediatric oncology PTCs. Table 3 shows patterns of referral to bone tumour services for children who were diagnosed during 1998-2007 with a sarcoma of the bones of the limbs. Overall, 85% of children were referred to the London or Birmingham services and 9% to the other three, smaller centres. The proportion referred to a large centre was higher for osteosarcoma, 89%, than Ewing sarcoma, 76%. Referral to bone tumour services was largely split along regional lines, with only South West England having substantial numbers of patients at both London and Birmingham. Of the three smaller centres, referrals to Newcastle and Oxford were mainly for patients resident in the same region, while all four referrals to Oswestry, which is situated near the border between England and Wales, were from Wales. Of the 12 patients from South West England with no record of referral to a bone tumour service, nine were diagnosed during 1998-2002 and only three during 2003-2007.

**Table 1 Referral of retinoblastoma patients by ophthalmological treatment centre, 2002-2009.**

 **Source: National Registry of Childhood Tumours**

|  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- |
|  |  | **London** | **Birmingham** | **Sheffield** | **Dublin** | **NR** | **Total** |
| Total | 137 | 195 | 5 | 6 | 7 | 350 |
| Laterality |  |  |  |  |  |  |
|  | Unilateral | 84 | 135 | 5 | 4 | 3 | 231 |
|  | Bilateral | 48 | 60 |  | 2 | 3 | 113 |
|  | NR | 4 |  |  |  | 2 | 6 |
| Previous family history |  |  |  |  |  |  |
|  | Yes | 21 | 20 |  |  | 1 | 42 |
|  | No | 116 | 175 | 5 | 6 | 6 | 308 |
| Year of diagnosis |  |  |  |  |  |  |
|  | 2002 | 26 | 22 | 4 |  |  | 52 |
|  | 2003 | 20 | 21 | 1 |  | 1 | 43 |
|  | 2004 | 15 | 28 |  |  | 1 | 44 |
|  | 2005 | 16 | 21 |  |  |  | 37 |
|  | 2006 | 14 | 25 |  | 2 |  | 41 |
|  | 2007 | 19 | 29 |  | 2 |  | 50 |
|  | 2008 | 15 | 24 |  | 1 | 3 | 43 |
|  | 2009 | 12 | 25 |  | 1 | 2 | 40 |
| Region of residence |  |  |  |  |  |  |
|  | North East SHA | 2 | 20 |  |  |  | 22 |
|  | North West SHA | 9 | 38 |  |  |  | 47 |
|  | Yorks & Humber SHA | 10 | 29 | 5 |  |  | 44 |
|  | East Midlands SHA | 5 | 19 |  |  | 1 | 25 |
|  | West Midlands SHA |  | 32 |  |  |  | 32 |
|  | East of England SHA | 20 | 5 |  |  | 1 | 26 |
|  | London SHA | 37 |  |  |  |  | 37 |
|  | South East Coast SHA | 12 |  |  |  |  | 12 |
|  | South Central SHA | 19 | 8 |  |  | 4 | 31 |
|  | South West SHA | 12 | 8 |  |  |  | 20 |
|  | Wales | 3 | 15 |  |  |  | 18 |
|  | Scotland | 4 | 21 |  |  |  | 25 |
|  | Northern Ireland | 4 |  |  | 6 | 1 | 11 |

**Table 2 Childhood liver cancer patients in the UK. Numbers of children receiving a liver transplant at one of the childhood liver disease centres, 1998-2007.**

**Source: National Registry of Childhood Tumours**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
|  |  | **Transplant** | **No transplant** | **Total** |
| Total | 30 | 183 | 213 |
| Tumour type |  |  |  |
|  | Hepatoblastoma | 27 | 120 | 147 |
|  | Carcinoma | 2 | 30 | 32 |
|  | Other | 1 | 33 | 34 |
| Years of diagnosis |  |  |  |
|  | 1998-2002 | 14 | 85 | 99 |
|  | 2003-2007 | 16 | 98 | 114 |
| Region of residence |  |  |  |
|  | North East SHA | 0 | 9 | 9 |
|  | North West SHA | 3 | 16 | 19 |
|  | Yorkshire & Humber SHA | 3 | 15 | 18 |
|  | East Midlands SHA | 1 | 13 | 14 |
|  | West Midlands SHA | 1 | 21 | 22 |
|  | East of England SHA | 3 | 11 | 14 |
|  | London SHA | 4 | 26 | 30 |
|  | South East Coast SHA | 4 | 14 | 18 |
|  | South Central SHA | 3 | 10 | 13 |
|  | South West SHA | 5 | 12 | 17 |
|  | Wales | 1 | 9 | 10 |
|  | Scotland | 1 | 16 | 17 |
|  | Northern Ireland | 0 | 10 | 10 |
|  | NR | 1 | 2 | 3 |

**Table 3 Childhood bone cancer in England and Wales. Referral to specialised bone tumour service of children with sarcoma of bones of the limbs diagnosed 1998-2007.**

**Source: National Registry of Childhood Tumours**

|  |  |  |  |  |  |  |  |  |
| --- | --- | --- | --- | --- | --- | --- | --- | --- |
|  |  | **London** | **Birmingham** | **Newcastle** | **Oswestry** | **Oxford** | **Other/none** | **Total** |
| Total | 160 | 183 | 18 | 4 | 16 | 24 | 405 |
| Tumour type |  |  |  |  |  |  |  |
|  | Osteosarcoma | 115 | 122 | 14 | 2 | 4 | 9 | 266 |
|  | Ewing sarcoma | 43 | 56 | 4 | 1 | 12 | 14 | 130 |
|  | Other & unspecified | 2 | 5 |  | 1 |  | 1 | 9 |
| Years of diagnosis |  |  |  |  |  |  |  |
|  | 1998-2002 | 86 | 95 | 7 |  | 7 | 15 | 210 |
|  | 2003-2007 | 74 | 88 | 11 | 4 | 9 | 9 | 195 |
| Region of residence |  |  |  |  |  |  |  |
|  | North East SHA |  |  | 14 |  |  | 1 | 15 |
|  | North West SHA |  | 54 | 1 |  |  | 1 | 56 |
|  | Yorkshire & Humber SHA |  | 38 | 3 |  |  | 2 | 43 |
|  | East Midlands SHA | 6 | 23 |  |  |  | 3 | 32 |
|  | West Midlands SHA |  | 30 |  |  |  |  | 30 |
|  | East of England SHA | 34 | 6 |  |  |  | 1 | 41 |
|  | London SHA | 58 |  |  |  |  |  | 58 |
|  | South East Coast SHA | 29 |  |  |  |  | 2 | 31 |
|  | South Central SHA | 21 |  |  |  | 15 | 2 | 38 |
|  | South West SHA | 12 | 13 |  |  | 1 | 12 | 38 |
|  | Wales |  | 19 |  | 4 |  |  | 23 |