HeadSmart: are you brain tumour aware?

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Abstract

Brain tumours are the commonest cancer cause of death in children. Early diagnosis is crucial in preventing worse neurological outcome in survivors, however diagnosis is difficult as presenting symptoms can be non-specific. In 2006 the median total diagnostic interval was more than three months in the UK, three times more than in the USA. "HeadSmart: Be Brain Tumour Aware" was launched in 2011 to amplify the impact of the RCPCH diagnostic guidelines published in 2008. By providing high quality guidance on assessment, investigation and referral as well as distributing symptom cards, signposting the website and providing e-learning resources, we have successfully enhanced awareness in health professionals and the public. Moreover, since the guidance, there has been a statistically significant reduction in the UK's total diagnostic interval from 14.4 weeks in 2006 to one of the shortest in the world at 6.7 weeks. This article reviews the progress that has been made and aims to highlight the advice that has proved useful in reducing the total diagnostic interval.

Keywords awareness campaign; brain tumour; HeadSmart; presentation; signs; symptoms

Case story

A mother initially presented with her 3 month old to the GP as she had concerns that he was leaning his head to one side and had a mild flattening on one side of his head. They were reassured that this would correct with time.

The timeline (Figure 1) shows the journey of this patient to diagnosis and sadly, death.

This is a true story. The child was diagnosed more than 3 months after initial presentation and saw many different health professionals. Unfortunately the initial symptoms of a brain tumour can be non-specific; head tilt is one of the symptoms with low awareness amongst health professionals. The many cases like these in the UK are what prompted the initiation of the HeadSmart campaign; the aim, to accelerate brain tumour diagnosis in children.

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Introduction

Early diagnosis of all cancers is currently a national priority in the United Kingdom, as set out by NHS England. We know that childhood brain tumours pose a diagnostic challenge for primary and secondary care; the signs and symptoms that precede diagnosis are non-specific, fluctuate in severity and can mimic other common illnesses. The presentation is very much dependant on the age of the child as well as the tumour location and biology. This cases emphasizes time and the acquisition of symptoms over time. It illustrates that the total diagnostic interval (time from symptom onset to diagnosis) is actually a sum of multiple intervals; this family saw many different health professionals and waited for different opinions along the way, which delayed the diagnosis.

In order to achieve earlier diagnosis for childhood brain tumours we need to address all of the above. The strategy required to reduce the time to diagnosis is to provide education, guidance and raise awareness amongst health professionals and the public and this is what prompted the launch of HeadSmart: Be Brain Tumour Aware www.HeadSmart.org.uk.

What is the size of the problem?

Brain tumours affect 1 in 2400 children under the age of 16 in the UK each year; that is 500 new cases each year. Childhood brain tumours occur at any age and account for a quarter of all childhood cancers. They are the second most frequent malignancy in children after leukaemia, and are now the commonest cancer cause of death. Five year survival rates for brain tumours have improved to over 70% but two-thirds of survivors are left with a mild or moderate disability.

The time from symptom onset to diagnosis, known as the total diagnostic interval (TDI), is one of the longest for all childhood cancers. In a study published in 1986, of 247 children with cancer, 80% of those with leukaemia and 84% of the children with Wilms' tumour were diagnosed within 4 weeks of symptom onset in comparison to 38% of those with a brain tumour. The international median TDI is reported as 8.5 weeks but a multicentre study in the UK between 2004 and 2006 showed a median TDI of 14 weeks.

Along the pathway of TDI, there is symptom progression. In the early stage, due to the rarity of the disease positive predictive values are null and void. In the later stages there is an accumulation of signs and symptoms which eventually become localizing; by this point their outcome is much poorer. A prolonged TDI in childhood brain tumours is associated with an increased risk of life-threatening neurological complications at presentation and a worse cognitive outcome in survivors. It has also been associated with a reduced likelihood of achieving complete tumour resection which is an important prognostic indicator in some tumour types.

What are the diagnostic difficulties?

The reasons for prolonged TDIs are multi-factorial. Firstly, the rarity of brain tumours means health professionals do not

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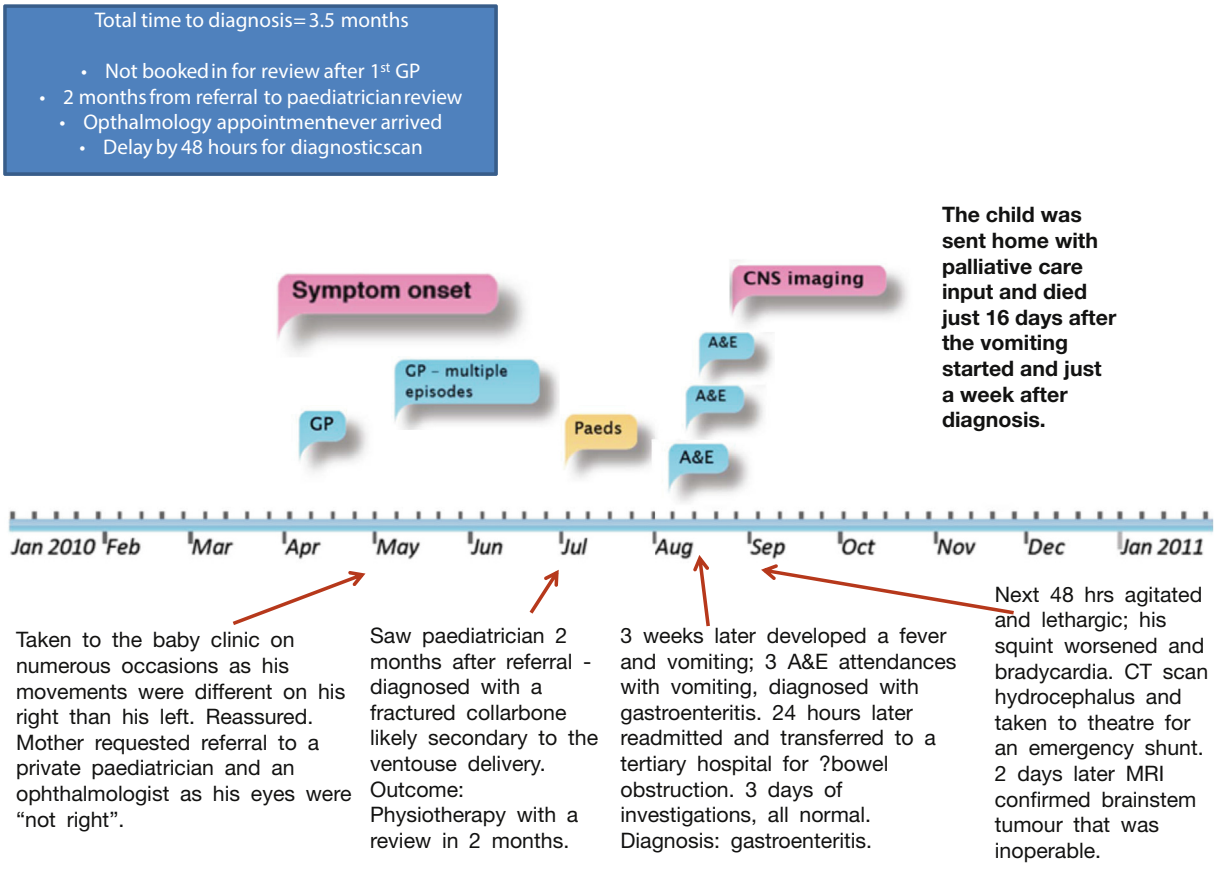

Figure 1 Timeline showed the journey of a 3 month old baby to diagnosis.

routinely consider this as a diagnosis when presented with non-specific symptoms.

The presenting symptoms of brain tumours include nausea, vomiting, headache and lethargy which are commonly misdiagnosed as gastroenteritis, migraine or behavioural problems. Furthermore the majority of children who present with a brain tumour have a completely normal neurological examination contrary to the beliefs of many health professionals. Brain imaging

Figure 2 A symptom card showing symptoms in different age groups.

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