

021

**SYMPTOMS AND QUALITY OF LIFE IN CHILDREN WITH INCURABLE CENTRAL NERVOUS SYSTEM (CNS) TUMOURS**

Lynda Brook,<sup>1</sup> David Walker,<sup>2</sup> Richard Grundy<sup>2</sup> <sup>1</sup>*Alder Hey Children's Hospital Liverpool, Liverpool, UK;* <sup>2</sup>*Queen's Medical Centre, Nottingham Christine Eiser, University of Sheffield, Sheffield, South Yorkshire, UK*

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**Background** Symptoms in children with incurable central nervous system (CNS) tumours are frequently managed with corticosteroids but 33% of children prescribed corticosteroids experience adverse effects and the overall effect on quality life is unclear.

**Aims** To determine the views of parents of children with incurable CNS tumours about symptoms, quality of life (QOL) and the benefits and problems associated with steroids.

**Methods** Semistructured interviews with the principal care giver of six children who died from a CNS tumour. Parents

were asked to describe their child's symptoms, QOL and benefits or adverse effects of treatments used to control symptoms. Verbatim transcripts were analysed using Thematic analysis.

**Results** Six key themes were identified: getting the diagnosis, treatment decisions, side effects of illness and treatment, adapting to the illness, facing death and professional support. The decision to stop curative treatment was influenced a number of factors including lack of efficacy or worry about the effects of the treatment on QOL. Children varied in the side effects that they had from the illness and its treatment. Sometimes, side effects from treatment were hidden by the effects of the disease, or were perceived as minor. Steroids were often perceived to have minor or positive side effects. Despite the need for parents to maintain a sense of normality for the child, both they and the child were often acutely aware of the limitations brought by the disease, especially when compared with other children. A rapid deterioration in the child's condition often alerted parents to end of life. Older children were usually aware that they were dying, even when parents tried to keep it from them, and they made plans for after their death.

**Conclusions** QOL is an important influence for treatment decisions in children with CNS tumours during palliative care. Symptoms and adverse effects of treatment appear less important than maintaining normal day-to-day activities.