Parents’ perceptions of obtaining a diagnosis of childhood cancer can include experiences of disputes and delays


QUESTION: What are parents’ experiences of obtaining a diagnosis of cancer in their children?

Design
Semistructured interviews.

Setting
Leicester, UK.

Participants
Parents of 20 children (age range 4–18 y) diagnosed with leukaemia, malignant solid tumour, or brain tumour, and who received treatment within the previous 4 months at a paediatric oncology unit. 4 families were of South Asian origin and the remaining families were white.

Methods
Semistructured interviews with one or both parents were held in their homes over a 7 month period. Interviews were open ended, but the interviewer used a prompt guide. Interviews were audiotaped and transcribed verbatim. Data were analysed using the constant comparison method assisted by NUD*IST software. Theoretical saturation was reached by the 14th interview. Medical records were also analysed.

Main findings
Parents were first alerted to their child’s illness by a range of medical signs and symptoms, and by behavioural and affective cues. Parents identified 2 groups of signs and symptoms: those for which innocent explanations could be found (eg, viral infection) and those consisting of unusual or frightening events (eg, fainting). The latter group of symptoms sometimes appeared after a period of the innocent symptoms, making parents feel that investigation was urgent.

After parents decided further investigation was needed, their accounts fell into 2 categories: those with a dispute with doctors (10 families) and those with no dispute (10 families). Parents were satisfied when their child had prompt and appropriate investigation and referral, but were not satisfied if they had to insist that the doctor take action. Parents who had disputes had to argue with doctors and demand investigations, rejecting common sense diagnoses. 7 families experienced lengthy disputes, which was more likely when the cancer was difficult to diagnose. 5 families were referred to secondary care, but some parents had difficulty persuading doctors and 2 were not referred at all. Those who were referred reported long waits, which caused them distress. Disputes continued when parents had access to secondary services. Some delays ended only if parents demanded action or if a medical crisis occurred. Parents’ accounts of delays were largely consistent with medical records.

Parents’ reactions to the diagnosis were affected by their experiences of obtaining the diagnosis. Some parents felt vindicated or relieved that something could finally be done, whereas others were shocked, with feelings of numbness and disbelief. Some parents who had disputes with doctors felt guilty, wishing they had been more effective advocates for their child.

Conclusions
Parents of children with cancer described their experiences of obtaining a diagnosis. Half of the families experienced disputes with doctors, delays in diagnosis, and felt doctors discounted their specific knowledge of their child.