

## When a child's central-line is infected: the impact on children and families

### **Background/Objectives**

Central-venous access devices (CVADs) are used in children with complex medical conditions to deliver life-saving treatments, such as chemotherapy and nutritional support. Infections of CVADs (central-line associated bloodstream infections; CLABSI), although rare, can result in prolonged hospital admissions, intensive care admissions and even death. As more children are facilitated to live at home, the impact of CLABSI on the emotional and mental health of the children at home and their families requires exploration.

### **Design/Methods**

Semi-structured interviews were conducted with parents of eleven children, and with twenty professionals. Interviews were digitally recorded and transcribed verbatim. Data were analysed using the constant comparative method. Data were collected as part of a larger study exploring care of invasive devices in the community.

### **Results**

Four families had personal experience of CLABSI, and all families were aware of other children who had experienced or even died of CLABSI. CLABSIs were unpredictable and children could deteriorate rapidly. Parents who had experienced CLABSI recounted the frightening and traumatic event and described vivid memories of their child's illness. All parents, irrespective of first-hand familiarity or not, experienced unrelenting fear that their child would develop an infection and die. Families described a state of constant vigilance where they continually monitored the child for signs of infection to ensure that they could receive treatment, further adding to their emotional workload. Hospital admissions further disrupted family life, affecting parents' work, school, hobbies and family celebrations.

### **Conclusions**

CLABSIs are associated with significant disruption to children and families. The threat of CLABSI results in significant emotional distress for families *in addition* to their existing burdens. Professionals should be aware of this emotional burden when counselling families about the risk of CLABSI. Children and families with experience of CLABSI may benefit from additional psychological support.