

Understanding the causes of disputes in paediatrics to develop pathways to dispute resolution in North East Scotland.

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The problem

Conflicts between parents and clinicians over the care of children with life-limiting conditions can reach the point where courts must intervene, causing distress, unwanted media attention and costs. This NHS Grampian study sought to understand the reasons for disputes, identify potential solutions and reduce the risk of a case coming before a Scottish court. This study was funded by the NHS Grampian Charity. We are indebted to all the participants who gave their time, and entrusted us with their honest, open and moving experiences of the care of a child with a life-limiting condition.

Summary of findings

What did participants agree on?

- that the impact of disagreements on parents and clinicians is significant and the damage can be vast.
- that there is a shared desire to avoid conflict.
- that significant improvements have already been made (more active anticipatory care planning, shift away from paternalism, inclusion of parents).
- that the costs of disagreements are emotional, psychological, familial, and social, as well as financial.

Where did parents' and clinicians' views differ?

- the timing of anticipatory care planning discussions.
- how soon specialist charities are signposted.
- the extent to which empathy is exercised.
- the use of technical language.
- the inclusion of parents in initial team meetings.
- the extent to which parents' understanding and expertise in their child is recognised and acted upon.
- the level of support provided to parents, and how peer support networks are highlighted.

Headline recommendations

- Embed empathy, as well as communication skills, more fully into clinician training, with further focus for those progressing within paediatrics as a specialism.
- Clarify the scope and increase the availability of "advocacy" for parents from specialist charities.
- Establish a single point of contact to liaise on behalf of parents and investigate whether this role is best provided through the NHS or the charitable sector.
- Ensure that anticipatory care planning discussions happen as early as possible in all cases.
- Provide greater institutional support for clinicians and more accessible fora to discuss difficult issues.
- Appreciate that one size does not fit all, and that clinicians need to adapt their approach for each family.