SIVERS, S., DOWNIE, M., TAI, J., MORGAN, H., TURNER, S., HERD, F., WORDIE, A. and DONALD, A. 2023. Understanding the causes of local disputes in paediatrics to develop pathways to dispute resolution in North East Scotland. Presented at the 2023 Royal College of Paediatrics and Child Health conference (RCPCH 2023), 23-25 May 2023, Glasgow, UK.

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

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Introduction and Objectives

Conflicts over the care of children with life-limiting conditions can reach the point where courts have to intervene, causing distress, unwanted media attention and costs. The decision in Charlie Gard's case in England included a plea for parties to mediate. No case has arisen in Scotland, where law and practice differ, but there are approximately 16,000 children with complex conditions (CHiSP2) where care might potentially be disputed. This NHS Grampian case study seeks to understand reasons for disputes, identify potential solutions (including mediation) and reduce the risk of a case coming before a Scottish court.

Methods

In-depth semi-structured interviews (online and face-to-face) with 13 NHS Grampian clinicians and 9 parents were conducted from which qualitative data were obtained on their experiences and views on disagreements about care, how decision-making is handled, what works well and what might improve existing approaches. This study was funded by the NHS Grampian Charity.

Some findings from clinicians

► Need to meet and resolve differences of opinion across disciplines before meeting with parents.
► Start conversations early.
► Build trust and bridges to come to common ground with parents.
► Cases are more common because of longer survival rates.
► *"The child is my patient and not the family."*
► Disputes arise when not all on the same page.
► Parents need to be more involved earlier (happens more when move to end-of-life care).
► Importance of giving the right information in the right format *"I provide a lot of information to families and that takes time … understanding why I make the decisions I do rather than just hearing about what the decision is, I think is probably quite important."*

Some findings from parents

► Have early conversations and use anticipatory plans.
► Medical teams don't trust parents' instincts *"We know our children the best, especially when they're really complicated."*
► Often dismissed *"[They] didn't listen to me … I was just utterly dismissed."*
► Reluctant to complain in case it takes focus off child.
► Need to understand whole family not just the child.
► Some discussions happen at the bedside where there isn't much privacy, but little scope to leave the bedside when also caring for their child.
► Feeling that conversations are rushed.
► Feeling they have to insist and push for meetings to avoid being excluded.
►Parents appreciate consultants who engage with their child as the primary focus *"The first person he spoke to was my son […] he kept involving him in the conversation."*

Some shared themes

► Recent shift from authoritarian to collaborative approaches.
► Need for one person to communicate with parents as a single point of contact.
► Recognise that parents feel intimidated by meeting with the whole team.
► Need to avoid jargon *"forget the medical terminology and big words."*
► Need more training in empathy.
► Parents are vulnerable in big team meetings "*You're very very vulnerable in a multidisciplinary meeting unless you're a very strong person."*

Conclusions – it is clear that conflict exists in Scottish paediatric care. Practice suggests that there are strategies which can be employed to minimise risk of intractable disputes. This requires further exploration and the development of tools to support clinicians and families.