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THE LAW SCHOOL





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

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Introduction, Objectives and Methods

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 case study sought to understand reasons for disputes, identify potential solutions and reduce the risk of a case coming before a Scottish court. In-depth semi-structured interviews with 20 participants (a mix of NHS Grampian clinicians and parents) were conducted from which qualitative data were obtained on their experiences of 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.

Findings

Support needs -

Identify an individual to act as an advocate for parents.

Further develop the support given to parents by the charitable sector, the importance and value attached to which cannot be under-estimated. Introduce the support services from specialist charities earlier.

Increase signposting to the range of support networks available to parents.

Address the need for clinicians to feel they have institutional support when making hard decisions.

Sharing and understanding information -

Improve clinical team-to-team communication.
Improve communication and rapport with parents.
Ensure parents have time to process information whenever possible.

Prepare parents before multi-disciplinary team meetings, and support parents during meetings. Include parents in the initial professional team meeting, although parents and clinicians disagree over this, and if professional-only team meetings continue, improve communications post-meeting to mitigate parents' sense of exclusion.

Key take-aways:

Embed empathy further into training.

Implement 'advocacy' for parents from the charitable sector.

Implement earlier anticipatory care planning. Provide clinicians with sufficient institutional support to make hard decisions.

Communication -

Maintain open and detailed discussions that avoid sugar-coating the information and embed open, frank and dispassionate discussions around the issue of death and dying, and the language of death.

Foster a balanced approach to the use of language

with parents, which recognises parental expertise and familiarity with the technical context where appropriate and maintains simplicity where necessary.

Be more consistent in recognising the expertise of parents in respect of their child and acting on it where clinically appropriate.

Provide more training for clinicians in empathy and consider more in-depth training for those specialising in this area.

Recognise and build on the willingness of both parents and clinicians to engage in informal practices around dispute resolution.

Timing and logistics -

Continue existing work to ensure that conversations about anticipatory care planning take place earlier, and outside crisis moments.

Provide appropriate safe spaces for conversations so that parents are not torn between leaving their child to go to a separate room, and their desire to stay by the bedside.

Identify an individual to be a single point of contact who will liaise with all types of other services for parents.