

Understanding disagreements between families and health care professionals over the care of critically ill children

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A literature review commissioned by the Nuffield Council on Bioethics (NCOB) and led by a University of Birmingham researcher, has shed light on the nature of disputes between health care professionals and families when it comes to the care of critically ill children.

Having a child that is critically ill is incredibly emotionally distressing and challenging. When conflicts arise between the medical team looking after a child, and the child's [family](#), about the child's care, tensions can run very high, and cases can end up in the courts.

Recent high-profile court cases, such as those for Charlie Gard and Alfie Evans, have highlighted the tensions that can arise and have led the Department of Health and Social Care to commission the NCOB to conduct an independent review of disagreements between families and health care providers, the findings of which are due to be reported to Parliament in October this year.

As part of this independent review, Dr. Kirsty Moreton, Associate Professor of Law at Birmingham Law School, conducted an in-depth literature review to get a clearer understanding of how these conflicts arise, the impact they can have on all parties, and how they might be resolved.

Dr. Moreton said, "My review has found that there are three groups that possible causes of disagreements over the care of critically ill children, fall into; internal, relational, and external."

"Internal causes can be things such as psychological responses, differences relating to religious and moral beliefs, and expectations of medical science and the idea of the 'good parent.' These internal causes affect the relationship between health care professionals and families, impacting communication, and behavior and leading to a breakdown of trust."

"This loss of trust may then lead to external causes, such as families turning to the internet and [social media](#) or the involvement of third-party organizations to replace advice, information or support offered by the medical team, or the desire to seek out alternative treatments."

The literature review outlines that while the adverse impacts of these disagreements on health care professionals are well documented, there is a gap when it comes to understanding the impact this has on the child. For families, the impact of ongoing disputes with health care providers can be traumatic and cause moral distress and relationship deterioration.

Some may find court proceedings difficult, but others find the opportunity to have their case heard in court to be helpful. Court cases can also damage the reputation of the NHS trust and the hospital involved in the case.

Dr. Moreton continues, "When disagreements about the care of an ill child arise, many steps are taken to try and come to an agreement between the families and health care professionals and avoid court action. However internal mediation and improved communication, which can be incredibly effective, need to be well-timed to work."

"My review found that when disputes escalate, third-party intervention, such as an expert second opinion, is not often effective. Instead, the use of Clinical Ethics Committees can have better results but is limited when it comes to disagreements on religious or moral values. The final option is to take cases to [court](#) when disagreements become the most severe."

Dr. Moreton concludes, "The reasons for these disagreements are complex and multifaceted, and it is highly unlikely that there will be a fix-all solution that avoids these disputes from happening in the future. But this literature review sets out the main sources of conflict so parties can understand one another better and can hopefully lead to identifying

opportunities for improved resolution methods."

"Having a critically ill child is one of the hardest things someone can go through, so it is imperative that communication and understanding are at the heart of the relationship between the medical team and the family, for the sake of that child and the well-being of all involved."

Natalie Michaux, Project Lead at the Nuffield Council on Bioethics, said, "This literature review is an important part of our work to better understand the causes of disagreements in the care of critically ill children and possible routes to their resolution. We extend our thanks to Dr. Kirsty Moreton for compiling such a comprehensive and informative review which will inform our findings, alongside our other wide-ranging evidence-gathering activities."

More information: Review: www.nuffieldbioethics.org/publications/cally-ill-children-2

Provided by University of Birmingham

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