

Disagreements in the care of critically ill children



OVERVIEW

- Protracted disagreements between parents and healthcare staff about the care and treatment of babies and young children who are critically ill can have damaging effects on everyone involved.
- Law and professional guidance state that decisions about care and treatment must be made in the child's best interests, and that parents and healthcare staff ideally should both agree to the care and treatment that is to be provided. Whether a different approach to decision making should be taken is the subject of current debate.
- The reasons why disagreements develop are wide ranging, but themes include: communication issues; differing perspectives, beliefs and values that lead to disagreements on, for example, what kind of risks justifiably could be taken; feelings of powerlessness for both parents and staff; and delays in seeking resolution interventions.
- The wider social and cultural context is also likely to be playing a role, including the increasing place of social media in public debate, easy access to online information about medical treatments, and the severe financial pressures facing the NHS.
- There is scope for policy makers and others to do more to support the creation of healthcare environments that foster good, collaborative relationships between parents and healthcare staff. The aim should be: good communication between families and staff and an understanding of differing perspectives; appropriate involvement of parents in discussions and decisions about the care and treatment of their child; timely use of effective resolution interventions in cases of disagreement; and attention to the profound psychological effects that disagreements can have on families and staff.

INTRODUCTION

The care and treatment of babies and young children who are critically ill often involves complexity and uncertainty, and disagreements can arise between parents and healthcare staff about the best course of action.¹ Sometimes these disagreements become entrenched, and the courts are required to arbitrate and make a decision, a process that can protract the disagreement further. Recent high-profile court cases in the UK have highlighted the damaging effects that these kinds of disagreements can have on everyone involved.²

This briefing note summarises the possible causes of disagreements between parents and healthcare staff, focusing on decisions about the care of babies and young children who cannot express their own views.³ We discuss the changing social contexts in which these issues arise and make observations about action that might be taken to prevent or more quickly resolve disagreements in future.⁴

WHO IS AFFECTED?

Protracted disagreements can have far reaching effects, particularly when they are played out in public as has happened in a number of cases. The effects of a protracted disagreement can be felt long after a decision has been reached. For the **child**, it can mean a delay in a decision about their care and treatment, during which time they might undergo many painful procedures in the intensive care unit.⁵ For the **parents and family of the child**, there can be severe distress and anxiety, commentary and abuse from external parties, and financial strain. **Healthcare staff** can also

experience significant distress and anxiety,⁶ and they might be subjected to intimidation and abuse. **Other parents** of critically ill children might lose trust in, or feel guilty about, decisions made about their own child. For **healthcare services** more broadly, protracted disagreements go against their general aim to maintain healthy relationships between staff and patients. There can also be significant time and resource implications, decreases in staff morale, a potential loss of public trust in the NHS, and damaging reputational effects both in the UK and abroad.

CURRENT LAW AND GUIDANCE

PROFESSIONAL GUIDANCE

Professional guidance for healthcare staff states that decisions about care and treatment must always be made in the child's **best interests**, and healthcare staff should work in partnership with parents to explore what treatment options might be best in the child's situation. Factors that should be considered include: clinical judgement about the effectiveness, risks and side-effects of a proposed treatment; the child's physical and emotional needs, and religious or cultural background; and the views of the parents and others who are close to the child.⁷

The guidance acknowledges that decisions about care and treatment can be complicated by **resource constraints**. Ideally, decisions about access to treatments should be fair, based on the patient's

ability to benefit, and made on the basis of clear and consistently applied local or national policies.

Before any kind of medical intervention can be given to a baby or young child, the **consent** of the parents or guardians must be sought by the healthcare team (except in emergency situations where immediate steps need to be taken). This also applies to decisions to withdraw or withhold life-sustaining treatment. Parents can request a particular course of action, but there is no obligation on healthcare staff to provide treatment that they do not believe to be in the best interests of the child. In practice, this means healthcare staff and parents of young children and babies ideally should both agree to the care and treatment that is to be provided through a process of shared decision making.⁸

If **disagreements** arise, there is a range of resolution interventions that can be used (see Box 1). However, there is a lack of evidence on the availability of different resolution interventions in UK hospitals, how often they are employed, and how effective they are in different contexts.⁹

The Royal College of Paediatrics and Child Health advice on managing conflict recommends that health professionals should: avoid giving inappropriate expectations, use palliative care teams early, recognise that parents will be under severe stress, support practitioners who may be caught up in the conflict, assign a lead clinician role to ensure continuity of information, and develop skills within the service to recognise the development of conflict. It also suggests external advice may be helpful, including ethical, legal and mediation services.¹⁰

COURT PROCEEDINGS

If a disagreement cannot be resolved, hospitals must apply to the appropriate court for an independent ruling before proceeding with a course of action that the parents do not consent to. The laws in the UK state that, where a court is involved in making decisions about a child, the child's welfare shall be the court's paramount consideration.¹¹ The United Nations Convention on the Rights of the Child says that "in all actions concerning children... the best interests of the child shall be a primary consideration".¹² The principle of best interests has become the 'gold standard' by which court judgments are guided.¹³

The number of cases that are referred to the High Court in England regarding the medical care and treatment of children is thought to be in the region of 10 per year, but precise figures are unavailable.¹⁴ Several court cases have been discussed publicly over the past few years, including the cases of Charlie Gard, Alfie Evans, Ashya King and Isaiah Haastrup.

BOX 1. RESOLVING DISAGREEMENTS

Disagreements are often resolved through **discussion** between healthcare staff and parents. To ensure discussions are holistic in nature, they can benefit from the involvement of others such as hospital chaplains, religious and community leaders, Patient Advice and Liaison Services (PALS), and palliative care specialists. Either party can seek a **second expert opinion**, although care should be taken to ensure this is viewed as independent by all parties. Some hospitals have

access to **clinical ethics committees**, which can help identify the ethical values underpinning the disagreement, but they vary widely in their membership and processes.¹⁵ **Mediation** involving a neutral mediator is increasingly recognised as an appropriate method for attempting to resolve paediatric healthcare disputes. **Court proceedings** are available when an independent and authoritative resolution is required.¹⁶

CHALLENGING CURRENT APPROACHES

There is debate about whether a different approach should be taken to decision making about the care and treatment of children.¹⁷ For example, 'Charlie's Law' seeks to avoid court orders that prevent parents seeking treatment that another hospital will provide, unless that treatment is believed to pose a risk of significant harm to the child (see Box 2).

Other suggestions include the creation of decision making bodies that could be referred to before involving the courts, such as quasi-judicial bodies or 'treatment review panels' that would consider requests for treatment taking into account the patient's situation and allocation of resources.¹⁸ Further examples of alternative approaches can be found in other countries.¹⁹

BOX 2. A THRESHOLD OF SIGNIFICANT HARM

Charlie's Law is a proposal being supported by the parents of Charlie Gard, Parliamentarians, academics, and health professionals. Charlie's Law would allow parents to seek 'disease modifying' treatment for their child, as long as there is a reputable institution willing to provide it and the proposed treatment does not cause significant harm. If a risk of significant harm was identified, a court could be asked to decide what would be in the best interests of the child.²⁰ Analogies have been made with care proceedings, where a court can only grant a care order where the child is suffering or is likely to suffer significant harm.²¹

In the case of Alfie Evans in 2018, the parents put to the court that the first question should be whether their proposals for Alfie's care would be likely to cause him significant harm. The parents wanted Alfie to be transported to a hospital abroad and undergo treatment that might enable ventilation to be continued at home. The judgment stated: "*The founding rule is that it is not lawful for them [doctors] (or any other medical team) to give treatment to Alfie which is not in his interests. A decision that, although not in his best interests, Alfie's continued ventilation can lawfully continue because (perhaps) it is not causing him significant harm would be inconsistent with the founding rule*".²²

WHY DISAGREEMENTS DEVELOP

Parents and healthcare professionals are not homogenous groups of people and every situation is different. Here we suggest four broad themes that have emerged in discussions of, and research on, why disagreements develop.

1. COMMUNICATION ISSUES

Poor communication between healthcare staff and families can contribute to the development of disagreements. This might include conflicting messages being given to families by different members of staff, the use of insensitive or inappropriate language and terminology, and confusion about what shared decision making means in practice. Communication issues such as these can escalate into a breakdown of trust, families and clinicians avoiding each other, and positions becoming entrenched.²³

The importance of open, clear and consistent communication is emphasised across a range of guidance for healthcare professionals. It is recommended that staff should have access to training and education in communication skills and ethics.²⁴ The effects of this kind of training have been studied in a London hospital. Participants were encouraged to empathise with patients and families by stepping into their shoes, and were taught skills to help them recognise and de-escalate conflicts.²⁵ Of the paediatric staff who experienced conflict in the six months following the course, 91% reported that the training enabled them to de-escalate the conflict.

2. DIFFERING PERSPECTIVES

Healthcare staff and parents can have differing perspectives, beliefs and values that lead them to disagree on the interpretation of medical information, on what kinds of risks justifiably could be taken, and on what constitutes a life worth living.²⁶ Parents and staff might also take a different view on how a decision about care and treatment should be made, and who should make it.²⁷ For example, in one study, most healthcare staff thought making the decision to withdraw a child's life support was too great a burden for parents to bear, but the majority of parents saw this as part of their parental responsibility.²⁸ Differences of opinion do not only occur between healthcare staff and parents. There can be disagreement among staff and within the child's family.

3. FEELINGS OF POWERLESSNESS

Parents and healthcare staff can experience feelings of powerlessness, which can contribute to the development of disagreements.

Parents can feel that they are excluded from medical conversations or are the last to be consulted, that they are not given access to important medical information, and that their expertise and role as parents are not adequately recognised. Parents are increasingly aware of variations in treatments on offer in different hospitals and regions, but usually have little choice over where their child is cared for.

If a disagreement is referred to the courts, parents are not entitled to legal aid, and their child is usually represented separately by an appointed guardian. There are significant differences between parents and hospitals in the resources that they can call upon, for example in order to obtain legal advice.

Healthcare staff can feel that they are not adequately supported by their employers to deal with conflict and possible abuse, and that they are vulnerable to public complaints that can take a long time to resolve and be highly stressful. There is also concern that, as staff are often prevented from engaging with the media, the full range of perspectives is not always aired in public debates about the treatment of critically ill babies and young children.

4. DELAYS IN SEEKING HELP

Resolution interventions, such as mediation or a court judgment, are often sought by the healthcare

team when disagreements have been going on for some time and have reached an entrenched stage. Barriers to seeking help earlier can include lack of availability or knowledge of resolution interventions, feeling that seeking help from a third party represents failure, and resource constraints. There are calls for more NHS hospitals to have access to clinical ethics committees and mediation services.²⁹

Children's palliative care specialists are often skilled communicators who take a holistic approach to supporting families of critically ill children, but they are often brought in to discussions at too late a stage. Misperceptions that such specialists only offer care and support at the very end of life, and patchy access to palliative care across the country, could be contributing factors to delays in seeking their input.³⁰ In addition, a survey of neonatal units in the UK found that many did not have counsellors, psychologists, psychiatrists or social workers to provide psycho-social support for parents.³¹

BOX 3. DECISIONS ABOUT EXPERIMENTAL TREATMENTS

Parents of critically ill children who have limited options might wish to access experimental or unproven treatments. A disagreement in 2014 between healthcare staff and the parents of Ashya King, a young boy with brain cancer, centred on the question of whether he should have a new type of radiotherapy called proton therapy. NHS England decided the benefits of the treatment were unproven for children with Ashya's condition and recommended conventional radiotherapy. Ashya's parents were unhappy with the treatment plan and took him overseas with the apparent intention of obtaining proton therapy at a private clinic in Prague.³² Doctors believed Ashya was at risk of significant harm and he was made a 'ward of court'. His parents were arrested in Spain and detained for several days, while Ashya

was admitted to a local hospital. However, the High Court decided that the parents' request for proton therapy was reasonable and Ashya went on to receive the therapy in Prague. In 2018, it was reported that Ashya, then 8 years old, had been cleared of cancer.³³ Some other cases that have reached the courts have centred on disagreements about experimental treatments.³⁴ As well as hoping for clinical improvements, parents might want to try such treatments as a way of expressing their compassion for their child, and ensuring that they did everything they could. A recent study has suggested that understanding the motivations of parents to seek experimental treatments could help healthcare staff consider options such as limited treatment trials, and reduce conflicts with families.³⁵

CULTURAL AND SOCIAL CONTEXTS

There are several societal and cultural factors that might be playing a role in the development of disagreements about the care of critically ill children.

- Advances in medicine mean that many children who otherwise would have died soon after birth can now be kept alive on ventilators and through other life sustaining interventions.
- Healthcare staff can find it difficult to initiate frank and open discussions about death and dying. There is a tendency to avoid having direct conversations about death across society more generally.³⁶

- There is easy access to a range of online information, of varying quality, about medical conditions and treatments, including experimental treatments and treatments that might be available in other countries (see Box 3).
- There is a range of views on how to approach decisions about the care and treatment of critically ill babies and young children. Differences in approaches to ethical dilemmas in medicine can be particularly marked between different countries and across different religions.³⁷
- Social media is having increasing prominence in people's lives. It presents avenues for parents

to express their concerns and anxieties, garner support, and crowdfund to cover legal costs and costs of treatment not offered by the NHS.³⁸ It enables other people and organisations around the world to promote their views, agendas and services.³⁹ There are calls for robust regulation and scrutiny of social media companies.⁴⁰

- The NHS is facing severe financial pressures, with most trusts across England, for example, spending over their budgets.⁴¹ As in other areas of healthcare, it is not always clear how limited resources are, or should be, taken into account in decisions about the provision of care and treatment for critically ill children.⁴²

AREAS OF ACTION

In this section, we make observations about actions that could help to prevent protracted and damaging disagreements developing in future, or to resolve them more quickly. The aim should be: good communication between families and healthcare staff and an understanding of differing perspectives; appropriate involvement of parents in discussions and decisions about the care and treatment of their child; timely use of effective resolution interventions in cases of disagreement; and attention to the profound psychological effects that disagreements can have on families and healthcare staff.

Those responsible for **national policy making** in relation to healthcare practice should consider:

- supporting NHS trusts across the UK to: develop processes for recognising and managing disagreements between parents and healthcare staff, such as introducing conflict management frameworks⁴³ and increasing timely access to resolution interventions; and gather data on the effectiveness of these processes;
- making ethics, communication, and conflict management training for paediatric healthcare staff more widely available, or even compulsory;
- improving access to and awareness of children's palliative care services;
- making independent advocates and financial support, such as legal aid, available to parents who are in legal disputes with hospitals;⁴⁴

- producing clear, accessible information for parents and others on current law and guidance on making decisions about the care and treatment of children, including what shared decision making means in practice, and how decisions about accessing experimental treatments are made;
- facilitating open debate and research on how limited resources should be and are being taken into account in decisions about provision of life-sustaining treatment for critically ill children.

Those involved in leading **NHS trusts and hospitals** should consider:

- exploring ways in which those parents who want to can be more involved in discussions and decisions about their critically ill child, including having access to their child's medical records and reliable research findings;
- providing parents with a trusted and appropriately trained healthcare professional as a central point of communication;
- ensuring timely referral to children's palliative care services, and providing parents with access to other appropriate support, for example from hospital chaplains, counsellors and psychologists;
- improving access to and awareness of effective disagreement resolution interventions in neonatal and paediatric intensive care units;

- ensuring healthcare staff involved in disagreements are better supported by, for example, developing conflict management frameworks, providing more psychological support, and protecting them from abuse and intimidation;
- exploring how healthcare professionals can be better supported to provide commentary to journalists when disputes about the care of critically ill children not under their care reach the news.

Research funding bodies and researchers should consider:

- carrying out research on current levels of access to and the effectiveness of different disagreement resolution mechanisms in hospitals, such as mediation, second expert opinions, and clinical ethics committees;
- exploring further the potential effects of any changes to the law and professional guidance on how decisions about the care and treatment of babies and young children are made, such as introducing a threshold of significant harm (see Box 2).

CONCLUSIONS

Some of the damaging effects of protracted disagreements between parents and healthcare staff about the care and treatment of critically ill children could be avoided if those disagreements were prevented from developing in the first place, or if they were more quickly resolved. The reasons why disagreements develop and continue are wide ranging, but themes include: communication issues; differing perspectives, beliefs and values that lead them to disagree on, for example, what kind of risks justifiably could be taken; feelings

of powerlessness for both parents and staff; and delays in seeking resolution interventions when a disagreement arises. The wider social and cultural context is also likely to be playing a part in the development and continuation of disagreements. Whilst there will always be instances where parents and healthcare staff disagree, there is scope for policy makers and others to do more to support the creation of healthcare environments that foster good, collaborative relationships between parents and healthcare staff.

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