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Medical Treatment Disputes and Children: An Empirical Analysis of Sixteen Years of Reported Judgments in England and Wales

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ABSTRACT

This article presents original analysis of sixteen years of reported case law concerning medical treatment disputes and children. These disputes often arise due to disagreement between healthcare professionals and family members about what healthcare is in the best interests of the child. We provide statistical analysis of a database of reported judgments, drawing out key themes arising from the cases. While much of the existing literature focuses on individual or high-profile judgments in this arena, our analysis takes a step back and looks at the broader themes that can only be understood by looking at the reported cases through an empirical lens. This broader view provides several new insights and we highlight key findings, including that: most cases are resolved in line with the public body's preferred outcome rather than the family; there is a relationship between the instigator of litigation and the outcome; and there is a relationship between the presence of religious factors and the outcome of the case. Overall, the article reinforces the need for further analysis of how medical treatment disputes are resolved, specifically further understanding about the use of informal mechanisms of resolution such as mediation and how the other factors identified influence court judgments.

KEYWORDS

Health law; medical treatment; children; best interests; mediation; religion; conflict

Introduction

There is increasing attention from scholars and policymakers on the causes as well as the effects of paediatric disputes. Scholarship has frequently highlighted poor communication and a breakdown in trust between parents and healthcare professionals (HCPs) as key features of many disputes which arise (Azoulay and Al 2009, Knickle *et al.* 2012, Brierley *et al.* 2013, Forbat *et al.* 2016, Auckland and Goold 2020, Parsons and Darlington 2021, Moreton 2023, Neefjes 2023). In addition to academic interest, attention from government is now evident, shown by the Department of Health and Social Care's commissioning of the Nuffield Council on Bioethics (NCOB) to report on the causes of disagreements concerning critically ill children. This report responded to a number of intractable and high-profile disagreements arising in recent years, such as the cases of

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Archie Battersbee, Tafida Raqeeb, Alfie Evans and Charlie Gard, which garnered a wide degree of press interest (*Barts Health NHS Trust v Hollie Dance and others* [2022] EWHC 1435 (Fam); *Tafida Raqeeb v Barts NHS Foundation Trust* [2019] EWHC 2531 (Admin); *Alder Hey Children's NHS Foundation Trust v Thomas Evans and others* [2018] EWHC 308 (Fam); *Great Ormond Street Hospital v Constance Yates and others* [2017] EWHC 1909 (Fam)). In the wake of the Archie Battersbee case, Southend MP Anna Firth publicly criticised the present framework (Farmer, 2022), calling for a public inquiry and new legislation known as Charlie's Law, which Charlie's parents have become advocates for, to provide better support to families faced with child's life-limiting illness (Charlie Gard Foundation 2024).

Academic scholarship regarding these disputes has proliferated, with a range of debates being engaged with, including discussion of the appropriate legal standard known as the best interests test (Auckland, Goold and Herring 2016, 2020; Auckland and Goold 2020). Some have argued that HCPs and parents lack a common understanding of best interests (Birchley *et al.* 2017, p. 930) and as recent high-profile cases have indicated, where parental authority ends is not a settled question. While this article will later show that determinations are most frequently in agreement with the position of HCPs, it is important to conceptualise best interests judgments as going beyond medical evidence. Other work has explored the appropriate role of clinical ethics committees (CECs), second opinions and mediation (Auckland, Goold and Herring 2016, Lindsey *et al.* 2023, Neefjes 2023). Moreover, philosophical discussion of the nature of existence, futility and the sanctity of life have dominated much of the discourse (Auckland, Goold and Herring 2016, Pope 2018). Here, we seek to develop the existing literature by carrying out a quantitative analysis of 16 years of reported judgments concerning the provision of medical treatment to children aged 17 years and under. We draw on a database of 116 reported judgments which we have compiled and carry out statistical analysis of, drawing on key themes arising from the cases, informed by the academic and policy discussions which have so far dominated the landscape. This article goes beyond the traditional narrow case analysis of much of the legal literature by taking a wider perspective through analysing all of the reported judgments over 16 years. This panoramic view allows us to draw out key themes and relationships from across the range of cases, and to highlight where the gaps are in our understanding and knowledge of how these disputes are formally and informally resolved.

We are aware of one other piece of research which similarly analyses reported case law in a systematic way. Neefjes' objective was to 'investigate the reasons why parents disagree with their clinicians in cases reaching the court and to estimate the number of cases in which mediation might have avoided litigation' (Neefjes 2023, p. 715). To do this she undertook an analysis of reported case law ($n = 83$) concerning medical treatment of children between 1990 and 2022. Her method was different from ours in several ways, including a different set of search criteria, a focus on applications initiated by public bodies only and only including decisions where there was a conflict about best interests. Our inclusion criteria were therefore broader to capture a wider range of healthcare disagreements that reach the courts.

This article starts with an outline of the background context of the conflict in paediatric healthcare, outlining the relevant legal frameworks and guidance which applies, before turning to the literature where we set out some of the key causes of and

responses to conflict in paediatric healthcare. We then set out the methods used for the original case law database analysis that informs the remainder of the article. Next, we provide the dataset which informs the analysis of this article, setting out descriptive observations as well as highlighting significant associations between several variables in our dataset. In particular, we draw four key conclusions. Firstly, that the reported case law shows that in most cases the courts agreed with the public body's preferred outcome and, moreover, that it is unusual for the courts to agree with the family. Secondly, that there is a statistically significant association between who brings the case to court and the outcome of the case. We link this to the importance of effective access to legal advice for family members. Thirdly, we show that there is an important relationship between the role of religion and the outcome of these cases. Finally, we consider the relationship between mediation, clinical ethics committees and the reported cases, suggesting that only limited conclusions can be drawn about the role of the former two dispute resolution mechanisms considering the limited evidence available in the reported cases about them. However, we suggest further research is needed to justify any substantive claims about their role.

Context for conflict in paediatric healthcare

Several of the high-profile disputes concerning the provision of medical treatment to children centred on the withdrawal of life-sustaining treatment. We note that very many other types of healthcare cases reach the courts for resolution in paediatrics. For instance, in Archie Battersbee's case, the parents did indeed oppose the withdrawal of mechanical ventilation, but also proposed that if it were to occur, that it should be done in a hospice rather than a hospital setting (*Hollie Dance & Paul Battersbee v Barts NHS Foundation Trust & Archie Battersbee* [2022] EWCA Civ 105).

When disagreements arise over which medical treatment is in a child's best interests, the appropriate statutory frameworks hinge on age and capacity. Decision-making power for those between 16–18 years old rests on a mixed legislative framework. The Family Law Reform Act 1969 (FLRA) set the age of majority in England and Wales at 18, though patients who have reached the age of 16 are presumed to be able to consent to treatment in a healthcare setting (FLRA s8). There is ongoing debate over whether this right encompasses the ability to refuse consent to treatment, and the prominence given to parental authority if the two opinions diverge (Jackson 2022, pp. 362–369). However, this operates in conjunction with the Mental Capacity Act 2005 (MCA) for 16 and 17 year olds, who must have mental capacity to make their own decisions about their healthcare.

To determine whether a person has capacity to consent to treatment, the MCA sets out criteria for establishing capacity. Under MCA s 3 a person is deemed unable to make a decision if they are unable to understand the information relevant to the decision, retain that information, use or weigh the information, or communicate their decision in any way, even when supported to do so. They must also be able to understand the reasonably foreseeable consequences of the decision, or of not making one. What this means for individual cases depends on the particular decision, but for giving consent to or refusing medical treatment it generally involves understanding the treatment, its risks and benefits, reasonable alternatives, the consequences of accepting or refusing the treatment, and the likely outcome of the treatment or

refusal. The second requirement, set out in MCA s 2, is that this inability to make a decision must be caused by an impairment of or disturbance in the functioning of the mind or brain. If a person is believed to lack the mental capacity to make their own decision, then medical treatment can be authorised by the CoP but only if it is in their best interests.

Unlike adults, who are presumed to have capacity unless rebutted under the MCA, children under 16 are presumed not to be able to provide consent. Decision-making authority ordinarily shifts to those with parental responsibility. Much like the MCA can rebut a presumption of capacity in adults, the rule that children under 16 are unable to consent is refutable. Gillick competence determines whether a child may consent to treatment. Those between 16 to 18 years old therefore require a more complex assessment in relation to their ability to consent or refuse consent to medical treatment (Griffith 2016). However, even a Gillick competent child's refusal to consent can be overridden. Lord Scarman's judgment in *Gillick* established that a minor must have 'sufficient understanding and intelligence' of a proposed course of treatment to be able to consent. The *Gillick* test considers the developmental maturity of the child alongside the seriousness of the decision, requiring an appreciation of the consequences, side effects and risks of failure to treat (*Re R (A Minor) (Wardship: Consent to Treatment)* [1992] Fam 11 [26A]). The Gillick test has been criticised as 'undermining rather than promoting ethically appropriate adolescent involvement' (Bart *et al.* 2023) and complicating clinical decision making processes for HCPs (Zimmerman 2019), nor has there ever been consensus on how the rights conferred via Gillick competence interlock with the principle of best interests decision making (Eekelaar 1994).

Where there is irresolvable disagreement between the decision-maker and HCPs, or between decision-makers such as two parents, application to the court may be necessary to provide a decision in the patient's best interests. Interestingly, and as we later show, it is highly unusual for the courts to disagree with the public body's view of best interests. Our data also show that it is often the Trust, rather than the family, who make the application to court. We may reasonably infer that litigated disputes so often favour the Trust because they have the institutional knowledge and financial means to seek legal enforcement. The former element also provides a basis for recognising 'winnable' cases, hence the higher 'success' rate.

Beyond the law there is also guidance for professionals regarding how to deal with disagreements about a child's medical treatment (General Medical Council 2022). Doctors have a duty to protect their health and well-being, and to listen to their views, as well as considering the role and responsibilities of parents and others close to them. Their primary duty, though, is to their patient (Re *R (A Minor)* [90]). Importantly, a child's best interests are not always limited to clinical considerations (*R (A Minor)* [92]). Parental opinion is an important factor in determining a child's best interests, and doctors should work in partnership with them when deciding about a child's treatment. Similarly, Royal College of Paediatrics and Child Health guidance *Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice* (Larcher *et al.* 2015) notes that paediatric doctors have a duty of care towards the child patient, but also towards the child's parents and family as a whole. A shared model of decision making is appropriate in most circumstances, with the guidance stating, 'Where parents do express views and these are reasonable, their values should carry great

weight in decision making' (Larcher *et al.* 2015, p. 11). However, sometimes the duty to benefit the child conflicts with a duty to the parents and this is where conflict can arise.

It should be noted that disagreement over paediatric treatment is not an uncommon occurrence, though litigation is rare. Interestingly, then, the vast majority of cases are resolved without recourse to the courts (Nuffield Council on Bioethics 2023, p. 10). There is also growing awareness of the negative effects of litigation. Often mentioned is the risk to the patient's wellbeing as the dispute continues, as well as the emotional and financial burden for parents. HCPs are subject to increased workplace pressure and reputational risk, while there is an opportunity cost to the NHS in covering the fees involved in court action. Litigation is therefore seen as a suboptimal last resort. We begin, then, from the point that most of the cases under review in this work, having reached a point where formal adjudication has been required, are uncommon in the broader field of medical treatment disagreements. As we later show, any perception that recourse to the courts furthers a parental rights agenda is unfounded, at least on an individual level, given that so few cases are decided in favour of parents and families. Some have argued that high profile litigation magnetises families to groups furthering a distinct parental rights and pro-life agenda. We know that in some cases, as a consequence of limitations on publicly available funds, families have turned to religious organisations for support such as the Christian Legal Centre, part of the Christian Concern group. These sorts of organisations do not solely focus on the provision of legal advice, but often also provide emotional and financial support for families. Although this may provide much needed support for family members at a difficult time, recourse to religious organisations may also distort the way that litigation is used in these cases if, for example, the case is presented as part of a wider religious or ethical perspective rather than reflecting the views of parents and families themselves. Moreover, in the Court of Appeal case, *Dean Gregory*, Jackson LJ stated: 'The court will not tolerate manipulative litigation tactics designed to frustrate orders that have been made after anxious consideration in the interests of children, interests that are always central to these grave decisions' *(Dean Gregory v Nottingham University Hospitals NHS Foundation Trust* [2023] EWCA Civ 1324 [22]). We draw no conclusions on that perspective in this paper except to make the point that litigation rarely results in the family's position being upheld and, in contrast, can result in public criticism of the parents and their supporters.

As scholarship in this area has highlighted poor communication and a breakdown in trust between parents and HCPs as key features of many cases which reach court, the suitability of alternative forms of dispute resolution remains a live, though under-researched, topic. Empirical research undertaken in this work indicates that the volume of cases is indeed rising. However, precise calculation of the increase is difficult to quantify for a number of reasons. Traditionally, cases of this type were not routinely published. New guidance was issued by the President of the Family Division in January 2014, introducing a presumption from February of that year that judgments should be made publicly accessible (Munby 2014). It is, however, unclear to what extent this has been achieved (Neefjes 2023, p. 217), and debate on the appropriate level of transparency continues (McFarlane 2021).

Emotionally fraught cases have increased attention on the suitability of alternative dispute resolution. In *Charlie Gard* for example, Francis J called for mediation's use in disputes of this kind (*Great Ormond Street Hospital v Gard, Yates and Gard* [2017]

EWHC 1909 (Fam) [20]). Yet the NCOB report included only limited evidence on mediation's use in this area, highlighting the gap between instinctive appeal and reliable evidence. Interestingly, in the NCOB's report almost a third of HCPs who had not engaged in mediation believed it could be helpful, and only 16% of survey respondents who had engaged in mediation had a negative view of it. None of the parental respondents to the call for evidence had personal experience of mediation, making conclusions as to its effectiveness difficult to draw. The reasons for this appear to vary, with some parents wanting mediation but not being offered it, whereas others had been offered it and declined. Further research is underway regarding mediation's effectiveness in these disputes (See Lindsey *et al*. 2023).

This paper highlights that mediation is explicitly mentioned only in a limited number of judgments in our database since 2007 ($n = 8$). Those which do so reference it with varying degrees of success. For instance, in *Knight* it was unclear there were any benefits (*Guy's and St Thomas' Children's NHS Foundation Trust v Pippa Knight and Paula Parfitt* [2021] EWHC 25 [6]), while it has also been seen as having the potential to detrimentally extend the length of a dispute (*The Newcastle Upon Tyne Hospitals NHS Foundation Trust v H (A Child)* [2022] EWFC 14 [25]). Conversely, in *Re X* it appears to have had significant success. While not completely resolving disagreement between parents and HCPs, the issues in dispute were narrowed (*Great Ormond Street Hospital v MX and FX and X (A Child)* [2020] EWHC 1958 [2–3]).

Recourse to litigation, despite its disadvantages, is perhaps a consequence of an unsettled allocation of decision-making authority, as well as the English legislative framework. Comparative analysis conducted by Auckland and Goold has suggested that the English experience is uncommon (Auckland and Goold 2020). Their work references the US and Switzerland (among others), where parental authority is stronger than in England, with the reduced influence of HCPs making litigation less likely. Conversely, Sweden and Spain are highlighted as states where there is greater deference to HCPs. They also point out that, unlike England, several countries have no clear procedural route for this type of dispute to reach the courts. The authors note that mediation may be beneficial in cases where there is scope for a compromised outcome, which would exclude cases where there is disagreement over the withdrawal of life-sustaining treatment. They conclude that a focus on consensus could potentially result in adverse treatment decisions, citing a Norwegian case study where (in a hypothetical setting) HCP's were found to defer to parental authority on life-sustaining treatment in circumstances which sometimes contravened the child's best interests.

What has escalated a dispute from difficult to intractable is not straightforward. Litigation addresses divergent views on appropriate treatment, but whether reaching the court stage is a result of a preventable breakdown in communication, divergent views on a child's condition, or fixed positions linked to sanctity of life arguments is not always clear – the root cause of disagreement may be obscured by circumstance. Once litigation is in motion, those with parental authority are no longer trying to change the mind of a HCP in an informal setting, but convince a judge in an adversarial one (Neefjes 2023, p. 717). The change in circumstance may result in under-emphasising some motivations which have diminished legal weight. For example, this work highlights religion as an explicit issue in many of the cases litigated, but this may be an underreported factor. The *Tafida Raqeeb* judgment tells us that courts are willing to engage with faith-based

arguments as a contributory factor to the best interests of a patient. However, in *JB* the court made their view clear that Raqeeb had not given any new primacy to faith-based arguments, and that they remained a consideration for the court, but never a conclusive argument (*Birmingham Women's and Children's NHS Foundation Trust v JB* [2020] EWHC 2595 (Fam) [30]). In our analysis below, we explore several of these themes further.

Methods

Our starting point in carrying out the analysis for this article was to prepare a database of all reported cases concerning children's medical treatment disputes over a 16 year period with the aim of carrying out statistical analysis of the reported judgments. We started this analysis with a publicly available table of cases concerning medical treatment for children (Bridgeman 2023) to identify cases in which parents disagreed with the healthcare professionals about the medical treatment for their children. This table contains information about the case name, age of child, medical condition, treatment/issue, procedure, significance of case and decision. Using this table as a starting point, we carried out a search using the Westlaw (www.westlaw.com.) and BAILII (www.bailii.org) databases, with the use of search terms 'medical treatment', 'medical', 'withdraw*', and 'health'. We then extracted cases so only patients aged 17 years and under were included. The results were used to compare against the publicly available table and to generate a new database with additional data recorded as relevant to the research aims.

From each judgment we aimed to collect the following data: the patient's age and medical condition(s), the medical treatment in question, the party that initiated the proceedings, the position of the parties (and whether it evolved in the course of the proceedings), the significance of the case, whether the judgment records that the parents invoked their religious beliefs, the decision of the court, the party with whom the court agreed (fully or partially), and any reference to the use of mediation, including both reference to mediation generally and whether mediation was used in the case. Most of these values were simple data points easily discernible from the judgment. However, the values for 'with whom the court agreed' were more complicated as there were several variables and possible interpretations of this. We separated out the variables to include: full agreement with family, partial agreement with family, no agreement with family, family agreed with public body, family views not represented, family views differed, full agreement with public body, partial agreement with public body, no agreement with public body. We also recorded whether the decision was in agreement with the patient, but due to the small number of cases where this data was available we have not included it in our analysis for this article. Partial agreement with family or public body would indicate that the court agreed with at least one aspect of that party's case, but may have disagreed or rejected other aspects of their submissions.

A case was included in our database when it met the following eligibility criteria: a) a judgment was published between 1 January 2007 and 31 January 2023; b) the patient was a child under the age of 18 c) the dispute was about what medical treatment should be provided to the child as being in his or her best interests. Cases concerning capacity to consent to treatment (and not the treatment itself), such as the cases about child's and parents' capacity to consent to hormonal treatment for gender dysphoria, were

excluded.[1] No other distinction was made with regard to the type of treatment. Disputes about life-sustaining treatment, major surgeries or experimental treatment were analysed alongside disputes around more minor medical interventions such as vaccinations. Both cases initiated by parents and those initiated by public authorities i.e. hospital trusts or local authorities were included in the review. If there was more than one judgment concerning the same patient, whether resulting from an appeal or concerning a separate issue related to medical treatment, each judgment was analysed separately unless indicated below. Judgments were analysed separately due to the possibility of different issues being raised at different times in the case and reference to issues such as religion, mediation and CECs arising in some judgments and not others.

119 judgments were identified and included in the initial database. However, three cases were removed completely due to the researchers feeling unable to confidently categorise the outcome data.[2] Therefore the data reported below investigates associations of categorical variables relating to medical treatment dispute cases ($N = 116$). In some analyses below, the number of cases analysed is smaller because some cases met our initial criteria but the judgments were missing information critical for our purposes (for example, in five judgments it was not possible to identify the public body's view on the case outcome).[3] The analyses were conducted using Statistical Package for the Social Sciences (SPSS). Firstly, the data was inputted to SPSS, then Pearson's Chi-square tests were conducted for all associations and descriptive statistics were measured. The measure of effect size was reported by Phi, where a small effect size is measured by 0.1, medium by 0.3, and a large effect size by 0.5.

Medical treatment dispute cases: a statistical analysis

We start by setting out key demographic details of the cases in our database. 85.3% of cases ($n = 99$) were heard before a High Court Judge, 10.3% ($n = 12$) before the Court of Appeal, 3.4% ($n = 4$) before the Supreme Court and 0.9% ($n = 1$) before an international court (the ECHR). These findings are to be expected given that it is relatively rare for cases to reach the appeal courts. Table 1 shows the distribution of the patient's age at the time of the hearing. This shows that the vast majority of cases (84.5%) concerned children under the age of 13 at the time of the hearing. However, within that broad age range, a large proportion are infants under the age of 24 months (40.5%), a finding in keeping with the characteristics of many of the disputes in the public discourse.

Table 2 indicates that the volume of cases is indeed rising, particularly in 2019 and 2020, though there are some notable exceptions. As shown in Table 3, end of life care was the most commonly reported medical issue causing a dispute (60.3%, $n = 70$) in the

Table 1. Frequency of patient's age at the time of hearing of medical treatment dispute cases.

Age at the time of hearing	N	Percent of cases
0–12 months	29	25
13–24 months	18	15.5
2–5 years	21	18.1
6–12 years	30	25.9
13–17 years	16	13.8
Missing age	2	1.7

Table 2. Frequency of the year of the judgment.

Year of judgment	n	Percent of cases
2007	1	0.9
2008	1	0.9
2009	2	1.7
2010	1	0.9
2011	1	0.9
2012	2	1.7
2013	4	3.4
2014	12	10.3
2015	8	6.9
2016	9	7.8
2017	10	8.6
2018	12	10.3
2019	5	4.3
2020	11	9.5
2021	18	15.5
2022	19	16.4

Table 3. Frequency of the medical issue relevant to the dispute.

Medical issue relevant to the dispute	N	Percent of cases
Vaccination	12	10.3
Other serious medical treatment	34	29.3
End of life care	70	60.3

current data. This was followed by other forms of serious medical treatment at 29.3% (e.g. *Wirral Borough Council v RT & NT* [2022] EWHC 1869; *Royal National Orthopaedic Trust v ZY & YY* [2022] EWHC 1328) and vaccination cases at 10.3% (e.g. *Re C (Looked After Child) COVID-19 vaccination* [2021] 2993; East Sussex County Council v SB, LH, VB & AB [2021] EWHC 1581). Table 4 shows that in 63.8% ($n = 74$) of cases, hospital trusts made the application to court. By contrast, in 25.9% ($n = 30$) of cases it was parents or other family who made the application. As we explore further below, there is a statistically significant relationship between who makes the application to court and the outcome.

Table 4. Frequency of who made the application to court.

Who made the application to court	N	Percent of cases
Patient	1	0.9
Local authority	11	9.5
Parents/family	30	25.9
Hospital Trust	74	63.8

Outcomes in medical treatment cases

In this section we analyse the data regarding the outcome in reported judgments concerning the medical treatment of children. The data reported show that there were statistically significant relationships between the frequency of court agreement with family and two other variables: 1) who made the application to court and 2) the medical issue in dispute. A statistically significant relationship means that the relationship is not explainable by chance alone and, instead, it is likely that the two variables are related. These data also show a statistically significant relationship between court agreement with

the public body and who made the application to court. These findings highlight that who made the application to the court may be an important factor affecting the outcome of the dispute. It is notable that public bodies made the majority of applications to court (73.3%, $n = 85$) in the time period under review.

In Table 5 we carried out a 4 × 6 chi-square test, which revealed a significant relationship between who made the application to court and whether the court agreed with the patient's family, χ^2 (15, $N = 116$) = 60.18, $p < .001$. The measure of Phi effect size for the association was $\Phi = .715$, indicating a large effect size. Table 5 shows that when the hospital trust made the application to court, the court did not agree with the family in 49 out of the 74 cases, were in full agreement with the family in only 3 of the cases, and were in partial agreement with the family in 6 of the cases. Similarly, when the parents and/or family made the application to court, the court were in no agreement with the family in 21 out of 30 of the cases, in full agreement with the family in only 3 of the cases and partial agreement with the family in one of the cases. This finding is reinforced in the data in Table 6 as well, which similarly confirm a significant relationship between who made the application to court, and whether the court agreed with the public body,[4] χ^2 (6, $N =$ 111) = 30.58, $p < .001$, with a large effect size ($\Phi = .525$). Overall, when the hospital trust made the application to court, the court were in full agreement with the trust in 93.2% of the cases, compared to no agreement with the public body in 1.4% of the cases. More

Table 5. Frequency of court agreement with family and who made the application to court.

Court agreement with family	Total frequency (percentage)	Who made the application to court	Frequencies	Percent of cases
Full agreement with family	8 (6.9%)	Hospital Trust	3	4.1
		Parents/family	3	10
		Patient	0	0
		Local Authority	2	18.2
Partial agreement with family	8 (6.9%)	Hospital Trust	6	8.1
		Parents/family	1	3.3
		Patient	1	100
		Local Authority	0	0
No agreement with family	73 (62.9%)	Hospital Trust	49	66.2
		Parents/family	21	70
		Patient	0	0
		Local Authority	3	27.3
Family agreed with public body	8 (6.9%)	Hospital Trust	8	10.8
		Parents/family	0	0
		Patient	0	0
		Local Authority	0	0
Family views not represented	10 (8.6%)	Hospital Trust	4	5.4
		Parents/family	0	0
		Patient	0	0
		Local Authority	6	54.5
Family views differed	9 (7.8%)	Hospital Trust	4	5.4
		Parents/family	5	16.7
		Patient	0	0
		Local Authority	0	0

Table 6. Frequency of court agreement with public body and who made the application to court.

Court agreement with public body	Who made the application to court	Frequencies[a]	Percent of cases[b]
Full agreement with public body	Hospital Trust	69	93.2
	Parents/family	21	84
	Patient	0	0
	Local Authority	8	72.7
Partial agreement with public body	Hospital Trust	4	5.4
	Parents/family	1	4.0
	Patient	1	100
	Local Authority	0	0
No agreement with public body	Hospital Trust	1	1.4
	Parents/family	3	12
	Patient	0	0
	Local Authority	3	27.3

[a]$N = 111$ as 5 cases are excluded due to missing data regarding public body's involvement or views.

specifically, in 88.3% of the cases, the court agreed with the public body, compared to partial agreement (5.4%) and no agreement (6.3%) with the public body.

To investigate whether the court's agreement with the patient's family is associated with the medical issue relevant to the dispute, a 4×6 Chi-square test was conducted in Table 7. Two cases were excluded due to missing data. The data revealed χ^2 $(10,\ N = 114) = 48.89$, $p < .001$. The measure of Phi effect size for the association was $\Phi = .615$, indicating a large effect size. Thus, there is a significant

Table 7. Frequency of court agreement with family and medical issue.

Court agreement with family	Total frequency (percentage)	Medical issue	Frequencies	Percent of cases
Full agreement with family	8 (6.9)	Vaccination	0	0
		End of life care	2	2.9
		Other serious medical Treatment	6	17.6
Partial agreement with Family	8 (6.9)	Vaccination	0	0
		End of life care	5	7.1
		Other serious medical Treatment	3	8.8
No agreement with family	73 (62.9)	Vaccination	6	50
		End of life care	52	74.3
		Other serious medical Treatment	15	44.1
Family agreed with public Body	8 (6.9)	Vaccination	0	0
		End of life care	7	10
		Other serious medical Treatment	1	2.9
Family views not represented	10 (8.6)	Vaccination	1	8.3
		End of life care	2	2.9
		Other serious medical Treatment	7	20.6
Family views differed	9 (7.8)	Vaccination	5	41.7
		End of life care	2	2.9
		Other serious medical Treatment	2	5.9

association between whether the court agrees with the patient's family and the medical issue relevant to the dispute.

Mediation and clinical ethics committees

The reported case law we have analysed highlights the relative infrequency of mediation, although with the caveat that it does not provide sufficient evidence regarding cases that have been mediated successfully or at pre-proceedings stage therefore not being referred to in any court judgment. 14 cases in our database refer to mediation in the judgment and eight refer explicitly to mediation having taken place. Importantly, the current data, as outlined in Table 8, include 93.1% cases that have no record of being mediated in the judgment, compared to 6.9% of cases recorded as being mediated.

We conducted a 2×3 chi-square test to investigate whether the court agreement with the public body is associated with whether the case was mediated. 5 cases were excluded from this analysis due to missing data, including one of the mediated cases due to missing court agreement outcome.[5] The data showed a significant association between whether the case was mediated and court agreement with the public body, χ^2 (2, $N = 111$) = 8.13, p = .017, with a small effect size (Φ = .271). Table 9 indicates that when the case was mediated, the court was in full (71.4%) or partial (28.6%) agreement with the public body. However, the results need to be carefully interpreted due to limitations of the small sample size of mediated cases and small effect size. Furthermore, where mediation is discussed in a court judgment it suggests that the mediation was not effective in that it did not resolve the disputed issues between the parties, although that is not to say it would not have other benefits. Therefore it is difficult to draw any strong inferences from this particular relationship about mediation's role in general, albeit the data may suggest that where mediation is used in a case which still proceeds to a judgment, there is an association with the court agreeing with the public body.

In addition to looking at the relationship between mediation and court agreement with the public body, we also carried out a 3×2 chi-square test which showed that there was a significant association between whether the case was referred to as having been mediated and whether a CEC was recorded as having taken place. The data revealed χ^2 (2, $N = 116$) =

Table 8. Frequency of mediation according to judgment.

	Yes	No/not recorded
Was mediation discussed in the judgment	14 (12.1%)	102 (87.9%)
Was the case mediated	8 (6.9%)	108 (93.1%)

Table 9. Frequency of whether the case was mediated and court agreement with the public body.

Was the case mediated	Court agreement with public body	Frequencies[a]	Percent of cases
Yes	Full agreement with public body	5	71.4
	Partial agreement with public body	2	28.6
	No agreement with public body	0	0
Not recorded in judgment	Full agreement with public body	93	89.4
	Partial agreement with public body	4	3.8
	No agreement with public body	7	6.7

[a]N = 111 as 5 cases are excluded due to missing data regarding public body's involvement or views.

25.41, $p < .001$, with a medium effect size ($\Phi = .464$). Table 10 shows the frequency with only 3 cases having both a mediation and a clinical ethics committee. However, as only 5 cases in our database refer to a CEC having taken place, $n = 3$ is a high proportion of those cases. There is an important limitation to the current findings: most of the data was not recorded in the judgments, and therefore it is difficult to draw any wider conclusions about the relationship between clinical ethics committees and mediation.

Table 10. Frequency of whether a clinical ethics committee took place and whether the case was mediated.

Clinical ethics committee	Was the case mediated	Frequencies	Percent of cases
Yes	Yes	3	37.5
	Not recorded in judgment	2	1.8
No	Yes	1	12.5
	Not recorded in judgment	4	3.6
Not recorded	Yes	4	50
	Not recorded in judgment	104	94.5

The role of religion

The variables analysed for Table 11 were whether religion was an issue in the dispute and court agreement with the patient's family. Two cases were excluded due to missing data. A 2 × 6 chi-square test revealed a significant association between whether religion was an issue and the court agreement with the patient's family, χ^2 (5, $N = 114$) = 12.75, $p = .026$. The measure of Phi effect size for the association was $\Phi = .331$, indicating a medium effect size.

Our analysis shows a significant association between a religious element in the dispute and court agreement with the patient's family. As can be seen in Table 11, religion was an issue in 30.2% of cases ($n = 35$). Of these 35 cases, the court did not agree with the family in 29 of those cases (82.9%), only fully agreeing with the family in 2 cases (*A (A Child) (Withdrawal of Treatment: Legal Representation)* [2022] EWCA Civ 1221; *Tafida Raqeeb v Barts NHS Foundation* Trust [2019] EWHC 2531 (Admin) *& Barts NHS Foundation Trust v Shalina Begum and Muhhamed Raqeeb & Tafida Raqeeb* [2019] EWHC 2530

Table 11. The frequency of whether religion was an issue and whether the court agreed with the patient's family.

Was religion an issue	Total frequency (percentage)	Court agreement with the patients family	Frequencies	Percent of cases
Yes	35 (30.2)	Full agreement with family	2	5.7
		Partial agreement with family	3	8.6
		No agreement with family	29	82.9
		Family agreed with public body	0	0.0
		Family views not represented	1	2.9
		Family views differed	0	0.0
No record	81 (69.8)	Full agreement with family	6	7.4
		Partial agreement with family	5	6.2
		No agreement with family	44	54.3
		Family agreed with public body	8	9.9
		Family views not represented	9	11.1
		Family views differed	9	11.1

(Fam)) and partial agreement in 3 (*Barts Health NHS Trust v Hollie Dance & Paul Battersbee & Archie Battersbee* [2022] EWCA Civ 935; *Manchester University NHS Foundation Trust v Fixsler* [2021] EWHC 2664; *In the Matter of ABC* [2021] EWHC 2574). These represent 14.3% of cases where religion was an issue, whereas the court was in full or partial agreement with the patient's family in a slightly smaller proportion (13.6%) of cases where the role of religion was not recorded in the judgment. However, these data are complicated by the fact that in the cases where there was no record of religion being a factor, there is a much wider range of outcomes, including cases where the family's views differed or were not represented in the judgment, meaning that in only 54.3% of those 'no recorded' cases did the court disagree with the patient's family. This is compared to 82.9% of cases where there was no agreement with the patient's family in the cases where religion was recorded as an issue, suggesting that religious issues may make the court less likely to agree with the family. A limitation of this analysis is that our database of cases included appeals and some of these appeal judgments do not report the role of religion in the dispute, even if we know that religion was raised as a factor in other judgments in the same case. We have only recorded religion as an issue where it was explicitly referred to in the specific judgment being analysed. Therefore this data may underreport the role of religion in a small number of cases where there were multiple judgments.

Discussion

Going to court is unlikely to favour families

The clearest finding from our analysis of reported judgments is that in the majority of cases (62.9%, $n = 73$), going to court does not result in a judgment in favour of the family's position. Despite rhetoric that families want their 'day in court' and discussion in cases such as *Indi Gregory* that families use litigation as a tactic, it appears from the reported judgments at least that engaging in litigation has little by way of outcome benefits for the majority of families, albeit families may still feel that the litigation was worthwhile for other reasons. Conversely, we know that litigation can be costly, time-consuming and stressful, and takes families away from day to day contact with their loved one. As Hayden J explained in *Great Ormond Street Hospital for Children NHS Foundation Trust v A Local Authority & Ors* [2022] EWHC 2596 [31]:

> Cases of this kind properly attract great public interest. It requires to be emphasised and to be understood that the overwhelming majority of these difficult decisions are taken by doctors and families, moving forward together by agreement. Recourse to the Court is rare . . . protracted litigation at the end of a child's life can be deeply scarring for all involved and where it can be avoided, it should be. It may be that there are lessons here which may have positive resonance in future cases.

Yet despite the likelihood of families getting the outcome they want from litigation being low, and the challenges of litigation being well known, family members may still feel it necessary to litigate to satisfy themselves that they did everything they could to protect their loved one. This is a common narrative across the breadth of reported case law, although it is worth noting Hayden J's further comments in the above case which appear critical of the notion of fighting, stating 'She has not drifted into perceiving the

competing alternatives as a 'battle', nor in any way led to misapprehend a change of position on her part as 'giving up'' [33]. Even though going to court is unlikely to result in a decision in favour of families, we remain of the view that the possibility of challenging healthcare decisions is an important safeguard against the exercise of power over the lives of individuals and these data should not be taken as an indicator of the futility of challenging medical decision-making. The right to bring a challenge, or respond to a request for a determination about a child's best interests, is an important one and we would not suggest that it should be removed or restricted in any way. What we do think these data show, however, are that the realistic prospects of success for most challenges will be relatively low. Family members contemplating litigation in disputes of this nature should not be under the illusion that a challenge to healthcare professionals is likely to be successful and the statistical evidence about the chances of success ought to be more widely understood.

Who brings the case to court matters

Noted previously is the significant association between who brings the case to court and the outcome. Due to the nature of the available data we are unable to ascertain the statistical direction of this relationship. However, as discussed earlier, we know that public bodies made the majority of applications to court (73.3% $n = 85$) during the period under review. There may be several reasons for this, including that if the public body wishes to take a particular course of action such as withdrawing or providing treatment then they need somebody with authority to give consent to enable them to take that course of action. Therefore it is most likely that public bodies will be the ones to issue proceedings in these cases. Additionally, there is a cost factor associated with issuing proceedings, with the public bodies most likely having the funds and expertise available to them to bring the case to court in a timely manner. Most families involved in a case concerning their child are unlikely to have the knowledge or expertise regarding litigation and, unless they are provided with timely and accurate legal advice, they may struggle to understand the intricacies of the litigation process. In contrast, Trusts are more likely to be well versed in this type of dispute, giving them an advantageous position when litigation is commenced. Previous disputes will have created institutional knowledge about how to handle disputes across the procedural and substantive aspects, including the advantage of a better understanding of which cases are more likely to be resolved in accordance with the views of HCPs, thus limiting the use of Trust funds on cases less likely to be 'successful' from their perspective.

Judges have repeatedly voiced concerns at cuts to legal aid acting as a barrier to bringing legal action and accessing sound legal advice, for example in *Great Ormond Street Hospital v Yates* [17]. It is worth noting Hayden J's comments in *Great Ormond Street Hospital for Children NHS Foundation Trust v A Local Authority & Ors* [2022] EWHC 2596 (Fam) in which he noted the benefit of having experienced family lawyers readily available to family members (at [33]). Some parties have turned to crowdfunding, as seen in the cases of *Gard* and *Raqeeb* (Bhatia and Birchley 2020), consequently increasingly the visibility of the dispute and potentially entrenching and aggravating positions between parties. Importantly, there have been recent changes to the legal aid rules; following implementation of the Civil Legal Aid (Amendment) Regulations 2023

(SI 2023/745), legal representation for parents of, or those with parental responsibility for, a child (aged under 18) facing the withdrawal or withholding of life-sustaining treatment will no longer require a means test. This may be beneficial for families to facilitate their access to legal advice from a broader range of sources than is currently possible. However, this only applies to end-of-life cases and also still requires a merits test, meaning that in many instances parents may still struggle to get reliable legal advice covered by the legal aid agency.

The role of religion

We know that religion plays a prominent role in the discourse around paediatric disputes (Brierley *et al.* 2013, Neefjes 2023, Nuffield Council on Bioethics 2023) but the ways in which it has been relevant across the case law is unclear. One of the only studies to explore this in a paediatric setting is Brierley et al's retrospective review which found (Brierley *et al.* 2013, p. 573):

> During the 3-year period 203 children had withdrawal or limitation of invasive care recommended by the medical team and in 186 cases families agreed that this was in the child's best interests. However, in the remaining 17 cases agreement could not be achieved with the families. We reviewed the case notes and found a predominant theme of expression of strong religious belief influencing the family's response to the critical illness of their child. Of these 17 initial cases, 6 were resolved by considering the best interest of the child, further time for the families and ongoing multidisciplinary discussions. However, 11 (65%) involved challenging protracted discussions, largely based upon the belief in the sanctity of life as a result of the parents' religious convictions.

This analysis provides an important insight into the role of religion in some of the most difficult conflicts in paediatric intensive care. However, what is not clear is what proportion of those other cases, where families did agree to withdraw treatment, also included religious aspects. This is important to understand because the argument that proceeds implies that it was the religious faith that prevented agreement, rather than some other factor possibly not always identifiable by the HCPs involved.

Looking more specifically at religion in litigated cases, prior analysis also confirmed that religion has a role in a sizeable portion of reported cases. For example, Neefjes identified religious beliefs as a factor in 39 out of 70 cases analysed in her dataset (Neefjes 2023, p. 716). As noted above, our database is drawn from a narrower timeframe and includes a wider range of reported judgments, which explains some of the differences in our findings. In our database, religion arises as a relevant issue in 30.2% of cases and in Neefjes' data, in 55.7% of cases. Somewhere between a third and half of paediatric disputes having a religious element to them is notable. The most recent census data confirms that, in England and Wales, 37.2% of people were recorded as having no religion with 46.9% recording religious beliefs (Office for National Statistics 2021). It should be expected that religious beliefs are likely to play a role in a proportion of paediatric disputes if the wider population statistics on religious beliefs are taken into account. Moreover, there is some evidence that religion is more likely to play a significant role in a person's life at times of crisis (Sibley *et al.* 2012, Stolz and Voas 2023), suggesting that a person's religious views may well be more pronounced when considering the life and health of their child.

It should come as no surprise, then, that religion plays some role in paediatric healthcare disagreements, but what is more noteworthy is that religion is significantly associated with the outcome of the dispute. This means that, based on statistical analysis of reported judgments, the relationship between religious beliefs being noted in the judgment and the outcome of the dispute is not governed by chance. We know from our data in Table 11 that courts mostly agree with the public body rather than family members in cases with a religious element – in 82.9% of cases there was no agreement with the patient's family where religion was recorded as an issue, suggesting that religious issues may make the court less likely to agree with the family. This infers that, even though religion is not a factor which ought to sway the court either way when analysing the best interests test from a doctrinal perspective, religion is likely to be a factor which impacts the outcome for parties involved in medical treatment disputes concerning children.

Mediation and CECs

Decreasing communication and a loss of trust are key markers of cases which result in litigation, frequently cited in disputes between HCPs and family members (*GOSH v MX and FX and X (A Child)* [2020] EWHC 1958 (Fam); *Manchester University NHS Foundation Trust v Fixsler* [2021] EWHC 2664 (Fam)). While many cases litigated reference a significant deterioration in relations between parties, Russell J was broadly critical of the closed-door nature of Trust decision-making in *Re X*, particularly the absence of parental involvement in the CEC. This was presented in stark contrast to the mediation process, in which the parents actively participated with their opinions voiced. However, we can see from the data presented above that reference to CECs and mediation is very rare in reported judgments, making it hard to draw any firm conclusions based on the case law alone. We would suggest that further research is undertaken to explore the specific overlap and relationship between mediation and CECs in paediatric disputes, as well as to improve understanding of more informal ways of resolving disputes, including CECs and mediation but also community based forms of resolution.

While mediation has been widely discussed in the literature, there is little empirical research into its effectiveness in paediatric cases. It is surprising that Neefjes' concluded that mediation would be unlikely to prevent litigation in religious or high conflict disagreements given the lack of evidence to show that disputes with those elements cannot be mediated. We do not suggest that mediation would certainly be able to resolve such a conflict where viewpoints and beliefs are profoundly divergent, but that the reported case law alone cannot support Neefjes' view. The evidence we do have suggests that the key to mediation's success in resolving disagreement is likely to centre on relational factors such as communication, participation and impact on relationships (Pincock 2013, Tallodi 2019, Irvine 2020, Wang *et al.* 2020, Lindsey 2022). Therefore if relationship breakdown is a central factor in paediatric disputes resulting in litigation, it is possible that mediation may well be a suitable step towards resolution, even in those most high-conflict cases. Furthermore, reported case law will inevitably exclude evidence of where mediation was successful in resolving a dispute because it is highly unlikely to result in a court judgment, particularly if the case was pre-proceedings when mediation took place. What we can see from the reported case law is that further evidence about the use of mediation and CECs is needed to determine the appropriate scope of its role here.

Conclusion

How best to respond to disagreements between HCPs, families and patients where serious conflict arises remains a controversial topic. Perspectives on the appropriate legal standard for best interests and the role of parental versus children's rights, continue to evade consensus. However, less attention has been paid to the root cause of conflict and other issues such as the role of religion, mediation, CECs, as well as to factors such as who brings the case to court and in whose favour the decision is likely to go. We have conducted statistical analysis of reported judgments concerning medical decision-making on behalf of children in England and Wales over a 16 year period to elucidate some of the factors which might be relevant to court decision-making in this context. We have shown that most cases are resolved in line with the public body's preferred outcome rather than the family's; that there is a statistically significant association between the instigator of litigation and the outcome of the case; that there is a significant relationship between religion and the outcome; and, finally, that while there is some relationship between the use of mediation and CECs, only limited conclusions can be drawn about the role of these mechanisms. These data will be an important source of evidence about how cases are decided and what factors might be relevant to their resolution.

Limitations of our analysis include that we have relied on reported judgments only, which we know are incomplete and only provide the account of the judge in the case. Furthermore, reported judgments are not able to tell us about which cases were successfully resolved before a judgment from the court, whether through informal resolution or formal non-judicial mechanisms such as mediation. We expect others will build on this data to explore in more depth the role of factors such as religion, mediation and CECs, as well as the relevance of various case characteristics.

Notes

1. The series of cases concerning Quincy Bell and the Tavistock and Portman NHS Foundation Trust have therefore been excluded.
2. The three cases that were removed completely due to the researchers feeling unable to categorise the outcome data were the two Supreme Court appeals in the *Charlie Gard* series of cases and the ECHR decision in that case. The first removed was that concerning the parent's application for permission to appeal the Court of Appeal judgment (8 June 2017) and the second concerned an application by the government regarding a stay of a previous order (19 June 2017). The third was the ECHR decision in *Charles Gard and Others v United Kingdom*, application no. 39793/17 (June 2017). These decisions were excluded due to the researchers believing the outcome would be unable to be accurately captured within our coding system for agreement with family, patient or public body.
3. The five cases removed due to an inability to accurately identify the public body's position were: *Z v Y* [2019] EWHC 2255, *Re B (A Child: Immunization) [2018] EWFC 56*, *In the Matter of M and N ; (no 2)* [2017] EWFC 49; *In the Matter of M and N* [2016] EWFC 69; *F v F (MMR Vaccine)* [2013] EWHC 2683.
4. 5 cases were excluded due to missing data.
5. The excluded mediation case was *In the Matter of M and N ; (no 2)* [2017] EWFC 49, which was a dispute between parents about vaccination and a case where the parents had engaged in mediation. The application involved the child's guardian. However, there was no public body involved in the dispute and therefore there was no outcome data relating to the public body, meaning that the case was excluded from our analysis.

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