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Involving parents in paediatric clinical ethics committee deliberations: a current controversy

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Abstract

In cases where the best interests of the child are disputed or finely balanced, Clinical Ethics Committees (CECs) can provide a valuable source of advice to clinicians and Trusts on the pertinent ethical dimensions. Recent judicial cases have criticised the lack of formalised guidance and inconsistency in the involvement of parents in CEC deliberations. In *Manchester University NHS FT v Verden* [2022], Arbuthnot J set out important procedural guidance as to how parental involvement in CEC deliberations might be managed. She also confirmed substantive guidance on the role of parental views in determining the child's best interests.

We agree that it is good practice to ensure that the patient voice is heard in ethics processes, but how that is achieved is controversial. Surely it is best that what matters most to a patient and their family, whether facts or values, is conveyed directly to those considering the moral issues involved, rather than via a prism of another party. The approach suggested in the *Verden* case has much in common with the process utilised by our CEC.

In this article, we commend Arbuthnot J's approach, provide an example of its effective operation and consider what it might mean for ethics processes.

Many Trusts and hospitals in the UK have Clinical Ethics Committees (CECs) to guide clinicians on cases, policy development and education.[1] The courts have long recognised the relevance of CEC advice in dealing with complex ethical matters.[2] And recently, professional guidance has placed additional emphasis on the role of CECs in resolving disagreements[3] and negotiating dilemmas in the COVID-19 pandemic.[4] In contrast to some countries, UK CECs lack a formalised structure.[5] There is no national guidance on their role, remit or who should be involved in their deliberations, though the UK Clinical Ethics Network has produced an important list of core competencies for CECs.[6]

In two recent legal disputes about the treatment of children, CEC procedures have been criticised by the English courts on the basis that they do not always sufficiently involve patients or families in their deliberations. The cases demonstrate the importance of hearing the patient voice in all ethics deliberations, whether paediatric or otherwise and raise controversial questions as to how - procedurally and substantively – that might be achieved, particularly when the patient lacks capacity.

In *Great Ormond Street Hospital for Children NHS Foundation Trust v MX & Ors,* Ms Justice Russell said that consultation with the patient and family is 'good practice' and that the absence of national guidance on the involvement of families in CEC deliberations was problematic.[7] We have previously considered this as part of a broader exploration of what ethical support in paediatrics is.[8] More recently, in *Manchester University NHS FT v Verden,*[9] Mrs Justice Arbuthnot set out important procedural guidance as to how parental involvement in CEC deliberations might be managed and confirmed substantive guidance on the role of parental views in determining a child's best interests.

The Verden case

The case, widely covered in the media,[10] involves William Verden, a 17-year-old described as someone who 'lacks capacity to conduct these proceedings and make decisions regarding his medical treatment due to his learning disability, autism and ADHD'.[11] William had renal failure due to nephrotic syndrome and required haemodialysis. The specific consideration before the court was whether William ought to be listed for renal transplant, given the likely burdens of the operation and post-operative care, or receive continuing haemodialysis, which William had initially struggled to tolerate.

The case had many nuances, but what we wish to highlight are (i) criticism of the ethics process involved in the case and (ii) reiteration of helpful guidance on the weight accorded to parents in such situations.

The ethics process

On the matter of process, Arbuthnot J said:

> *Ms Butler-Cole QC was critical that the parents' views had not been taken directly by the Committee whilst a number of clinicians had attended to give theirs. It did seem to me that a better approach might be to have a meeting which is divided into two parts, one where the parents attend to give their views and the second when the clinicians attend. The Ethics Committee would then have a better idea of William's quality of life, his wishes and the position of the family.'*[12]

We think this is right. In our view, it should be general good practice to invite patients and / or parents or carers to the meetings of CECs discussing the case so that they can both hear what the issues are and present their own opinions. Two of the authors are members of the GOSH CEC. Our practice is to invite parents to CEC Ethics Case Reviews (ECR) about their children routinely. In fact, a recent UKCEN survey confirmed we are the only UK committee – including those predominantly seeing child cases – to invite relatives or patients into the ethics process regularly.

It would seem to us sensible not to have clinicians and parents attend at the same time, though there may be overlap. There may be confidential matters that cannot be shared. There may be an understandable reluctance on the part of clinicians to speak openly and frankly if the parents are present. There is also good reason to avoid creating, in actuality or appearance, an antagonistic confrontation of clinical and parental views.

Evolution of ECR parent-attendance

When the first parent attended an ethics meeting in 2008, driven by lay members rightly concerned about openness and transparency, there was no roadmap or experience from other centres. The initial parent seemed to treat the meeting as a quasi-legal process where he gave evidence to a committee room full of strangers deciding about his child. This was, for us, not some short-lived failed experiment but certainly needed more thought and design, a description of which follows. Notably, the process continues to evolve but essentially consists of a pre-brief, attendance at ECR, and a post-meeting debrief, occasionally with long-touch follow-up.

Pre-brief: Parents were initially prepared by the Patient Advocacy Liaison Service (PALS) with chaplaincy where appropriate, but the system has developed, and now the chair of each ECR will meet the parents and child, if appropriate, and discuss ethics and the ECR process, listen to their thoughts, address questions and provide a leaflet with contact information.

ECR: Parents +/- the child attend the middle third of the meeting and are introduced to everyone present and their roles explained. Parent feedback has taught us that ‘crowd control’ is crucial, with as many as six hospital teams involved and sometimes referring hospital and community teams. A few of the ethics team attend, ideally including a ‘previous GOSH parent member’ rather than the full committee, and non-vital/decision-making clinicians leave for the ‘family’ section. Parents can be supported by family members, a friend or faith/community leaders. Recording is generally not permitted.

Parents/the child explain their thoughts, hear the teams’ thoughts, are asked questions by the ethics team, and have a chance to ask questions of the ethics team and clinicians.

Post ECR: The chair and lead clinician meet with the parents and child within hours to discuss the ECR conclusions. A summary is placed in the notes within days.

Few ECR meetings deal with withdrawal of life-sustaining treatment, most involve innovative or experimental therapy outside research ethics remit in what is, after all, a rare disease hospital. These are often n=1 treatments, extended access, or, more simply where inadequate data exists for formal research, but *reasonable* clinical opinion supports use. [13]

COVID-19 disrupted this process, most strikingly enforcing video-conferencing. The Luddite Director (JB) now sees the advantage of this with families more at ease in their home environment or familiar ward space, together with easier attendance for off-site/busy clinicians. His concerns about the ability to be candid in this format have not been borne out.

Systematic feedback from clinicians has shown appreciation of ECRs in terms of the support it provides them, their team and their patients and family and the space to deliberate matters of morality. Parents overwhelmingly support the process, many suggest it illustrates how the institution values their child whilst, to some extent, reducing power imbalances. The exceptions have been cases either where serious difficulties exist with the institution's teams, or where parent attendance has not occurred, [14] due to their unavailability or, until recently, referring team veto.

The role of parents in best interest decision making

Because William was 17, his case was heard by the Court of Protection on the basis of the principles set out in the Mental Capacity Act 2005. Section 4(6) requires consideration, where ascertainable, of 'the person's past and present wishes and feelings' and their' beliefs and values'. Section 4(7) requires that, where practicable, those interested in the person's welfare are consulted. In *Aintree University Hospitals NHS Trust v James*, the Supreme Court was clear that the patient's perspective is central to decision making even though that perspective will not always prove determinative:

> *The purpose of the best interests test is to consider matters from the patient's point of view. That is not to say that his wishes must prevail, any more than those of a fully capable patient must prevail. We cannot always have what we want.*[15]

According to Baroness Hale in *Aintree*, a determination of best interest considers 'welfare in the widest sense, not just medical but social and psychological'.[16]

In relation to younger children, where the Mental Capacity Act does not apply, the courts are clear that the views of parents and others involved in the care of the child are important to help determine the child's point of view.[17] There is, therefore, considerable alignment in the relevance of the views of family members to the best interests of a person who lacks capacity in cases in the High Court and Court of Protection.[18] This is true even when the child in question is very young and has not yet formed values and beliefs. In the *Verden* case, Arbuthnot J set out the court's approach to the relevance of parental views:

> *The views and opinions of both the doctors and the parents must be considered. In reaching its decision the court is not bound to follow the clinical assessment of the doctors but must form its own view as to the child's best interests.*
>
> *The views of the parents may have particular value in circumstances where they know well their own child. However, the court must also be mindful that the views of the parents may, understandably, be coloured by emotion or sentiment.*[19]

Clinicians, like the courts, should make an assessment of overall (rather than purely clinical) best interests.[20] In a court case the judgment should indicate what weight has been attached to medical and non-medical factors.[21] The CEC has an advisory rather than an adjudicatory function, but can usefully set out the relevant medical and non-medical factors and advise clinicians as to how they might be balanced. In ethics processes, it is important to clarify the different reasons one might –

and should – have for hearing the parents' views. Disentangling the good and the bad reasons matters when one is justifying their attendance. First, the good reasons:

First, parents may be better, indeed best placed to know certain things about their child, such as what the child values and enjoys, what contributes to that child's quality of life as it is and as it might be.[22] They might be best placed to identify certain relevant considerations that would affect the likely outcomes of different treatment pathways, for instance, the degree of unmanageable resistance to the administration of a drug or other treatment.

Second, parents can testify to the contribution they and the family generally make to the child's life.[23]

Third, it may well be that the principal burden of continuing treatment falls on the parents. If that is the case, it is vital that parents can speak honestly about what they believe is possible and tolerable.[24] It is not in their interests – and not in the best interests of the child – that they should be subject to impossible or unreasonable demands in caring for the child. That is the case however much they might wish to insist that they can discharge the duties of care.

Now for the bad reasons:

First, parents are not privileged decision-makers for their child, in the sense that since the child is theirs, it is their choice as to what is done. Of course, parents are given the presumptive liberty to make decisions in the normal course of events. Indeed, it is best for the child that parents do make day-to-day decisions. Outside the context of medical treatment cases, this is subject to a harm principle that permits the state, as *parens patriae*, to intervene and assume the role of protective guardian when parents act in ways that risk seriously harming or do actually seriously harm the child.[25] In medical treatment cases, it is subject to the welfare principle, as McFarlane LJ made clear in *Yates and Anor v Great Ormond Street Hospital for Children NHS Foundation Trust:*[26]

> *112. … As the authorities … underline again and again, the sole principle is that the best interests of the child must prevail and that must apply even to cases where parents, for the best of motives, hold on to some alternative view.*

Second, and relatedly, parents do not know better than anyone else what is best for the child. They know better certain things that are relevant to an assessment of best interests. But that assessment is a holistic one that takes account of not just medical considerations but the quality of life and the circumstances of the child. It is a difficult assessment that can be impacted by *'abiding love and fierce devotion and the amplifying effect on those emotions of the flattering voice of hope;'*[27] it is not one that either parents or clinicians are uniquely best placed to make.

Applying the best interests standard

Having said all of the above, it is important that CECs are clear as to the standard to which they hold parents accountable. The 'best interest' standard has long been subject to criticism for its indeterminacy, its lack of clear justification, and its demandingness.[28] Critics have suggested that, in the context of clinical care decisions, we should not hold parents to the best interests but to the harm standard, intervening only when the latter is breached,[29] and thus grant parents a 'zone of discretion' so long as they do not subject their child to harm.[30] Or we might only require that parents do what is good enough and not what is best.[31] As intimated above, in court the best interests and not a significant harm test applies. When the test is applied by clinicians, and correctly construed to encompass both medical and wider emotional interests, there is often scope to accommodate a range of views. Turning again to McFarlane LJ in *Yates and Anor v Great Ormond Street Hospital for Children NHS Foundation Trust:*

> *112. [I]n many cases, all other things being equal, the views of the parents will be respected and are likely to be determinative. Very many cases involving children …. never come to court because a way forward is agreed as a result of mutual respect between the family members and the hospital, but it is well recognised that parents in the appalling position that*

> *these and other parents can find themselves may lose their objectivity and be willing to "try anything", even if, when viewed objectively, their preferred option is not in a child's best interests.*

As Jo Bridgman has eloquently argued, where the course of action favoured by parents conflicts with professional obligations to their patient, clinicians may be unable to compromise.[32]

Whatever standard is adopted, CECs should be open, clear and transparent in their ethical reasoning and they should also ensure that the standard they make use of is legally defensible.

Benefits and risks: concluding thoughts

Giving a voice to patients and parents, and involving them in discussions about the child's care, is surely essential. We reiterate our agreement with the views of Arbuthnot J on this and again cite the good practice of the GOSH CEC. Such a process has benefits and risks. Amongst the former is most obviously the recognition of the child and parents' right to have their views heard. So long as the process is clear, consistently employed, and known to all relevant parties it also has the benefit of ensuring that any eventual decision has taken into account the views of relevant parties. It avoids any subsequent criticism by relevant parties of having been excluded from decision-making and puts the patient at the centre of CEC advice.

The risks derive from false expectations. A CEC recommendation is not a decision; that must rest with the clinicians. [14] The involvement of the patient or parents does not guarantee agreement between them and the clinicians. Nor is the CEC a body equipped or trained to mediate should disagreements persist, and perhaps take on an antagonistic form. There are risks that the issues at stake in any case – medical, legal and ethical – may not be correctly or fully understood. And there are risks that patients and parents invited to CEC meetings may sometimes struggle to articulate their concerns and values in an environment that, despite the best efforts of the CEC, they might find intimidating.[33]

Yet, when CECs advise clinicians or Trusts in cases where a patient's best interests are disputed or finely balanced, it is irrefutable that the patient's voice must be heard. Relaying the patient or family's voice second-hand is, of course, possible, yet as in the *Verden* case, risks creating concern that their views are not understood or given the correct level of importance by the ethics process.

Above all, it is important that CECs, clinicians, families and patients are aware of their role, its importance and also its limits.

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[1] Larcher V. Role of clinical ethics committees. Archives of Disease in Childhood 1999;81:104-106. doi:10.1136/adc.81.2.104

[2] See for example *Ms B v An NHS Hospital Trust* [2002] EWHC 429 (Fam), [10] (Butler-Sloss P). <https://www.bailii.org/cgi-bin/format.cgi?doc=/ew/cases/EWHC/Fam/2002/429.html> accessed 28 April 2022.

[3] General Medical Council, Decision making and consent (London: 2020), para 92. <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/decision-making-and-consent> accessed 28 April 2022.

[4] Royal College of Physicians, Ethical dimensions of COVID-19 for frontline staff (London: 2 April 2020), para 5. <https://www.rcplondon.ac.uk/file/20551/download> accessed 28 April 2022.

[5] Slowther AM, McClimans L, Price C. Development of clinical ethics services in the UK: a national survey. Journal of Medical Ethics 2012;38(4):210–4 doi:10.1136/medethics-2011-100173; Brierley J, Archard D, Cave E. Challenging misconceptions about clinical ethics support during COVID-19 and beyond: a legal update and future considerations Journal of Medical Ethics 2021;47:549-552 doi:10.1136/medethics-2020-107092.

[6] Larcher V, Slowther A-M, Watson AR. Core competencies for clinical ethics committees. Clinical Medicine 2010;10(1):30. doi:10.7861/clinmedicine.10-1-30

[7] *Great Ormond Street Hospital for Children NHS Foundation Trust v MX & Ors* [2020] EWHC 1958 (Fam)

[8] Brierley J, Cave E, Archard D. Ethical advice in paediatric care. Archives of Disease in Childhood 2022;107:e18 doi: 10.1136/archdischild-2021-322671

[9] *Manchester University NHS Foundation Trust v Verden & Anor* [2022] EWCOP 9. <https://www.bailii.org/cgi-bin/format.cgi?doc=/ew/cases/EWCOP/2022/9.html> accessed 28 April 2022.

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[10] See for example Brown M. Judge says autistic teenage boy with rare kidney disease can seek transplant. *The Guardian* (8 March 2022) at <https://www.theguardian.com/society/2022/mar/08/judge-says-autistic-teenage-boy-with-rare-kidney-disease-can-seek-transplant> accessed 28 April 2022.

[11] *Manchester University NHS Foundation Trust v Verden & Anor* [2022] EWCOP 9, [1].

[12] *Manchester University NHS Foundation Trust v Verden & Anor* [2022] EWCOP 9, [106].

[13] Larcher V, Turnham H, Brierley J. Medical Innovation in a Children's Hospital: 'Diseases desperate grown by desperate appliance are relieved, or not at all'.Bioethics. 2018 Jan;32(1):36-42.

[14] Brierley J, Archard D & Cave E. Challenging misconceptions about clinical ethics support during COVID-19 and beyond: Role, remit and representation. Journal of Medical Ethics 2021;47(8):549-552 doi:10.1136/medethics-2020-107092

[15] [2013] UKSC 67, [45] (Baroness Hale) cited in *Manchester University NHS Foundation Trust v Verden & Anor* [2022] EWCOP 9, [110].

[16] [2013] UKSC 67, [39].

[17] *Gillick v West Norfolk AHA* [1986] 1 AC 12, 184 A (Lord Scarman); *In Re R (A Minor) (Wardship: Consent to Treatment)* [1992] Fam 11, 22 (Lord Donaldson MR); *In Re A (Children) (Conjoined Twins: Surgical Separation)* [2001] Fam 147, 178 (Ward LJ).

[18] See, for example, reference to *Aintree v James* [2013] UKSC 67 in *Dance & Anor v Barts Health NHS Trust & Anor* [2022] EWCA Civ 1055, [17]-[21] (McFarlane P).

[19] *ibid*, [115 f] quoting MacDonald J in *Kings College Hospital NHS Foundation Trust v Hasstrup* [2018] EWHC 127 (Fam), [69].

[20] *Birmingham Women's and Children's NHS Foundation Trust v JB & Anor* [2020] EWHC 2595 (Fam) [30] (Hayden J) and see Cave E, Brierley J, Archard D. Making decisions for children—accommodating parental choice in best interests determinations. Medical Law Review 2020;28(1):183-196 doi:org/10.1093/medlaw/fwz038

[21] *Dance & Anor v Barts Health NHS Trust & Anor* [2022] EWCA Civ 1055, [62] (McFarlane P).

[22] *Yates and Anor v Great Ormond Street Hospital for Children NHS FT & Anor* [2017] EWCA Civ 410, [29] (McFarlane LJ).

[23] *An NHS Trust v MB* [2006] EWHC 507 (Fam), [16] (Holman J).

[24] *Re T (A Minor) (Wardship: Medical Treatment)* [1997] 1 All ER 906, CA.

[25] Children Act 1989, s 31.

[26] [2017] EWCA Civ 410, [89]-[105].

[27] *Barts NHS FT v Raqeeb* [2019] EWHC 2530 (Fam) [1] (MacDonald J).

[28] Archard, D. *Children, Rights and Childhood*, 3rd edition (2014) Abingdon: Routledge, 112-116.

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