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Clinic, Courtroom or (Specialist) Committee: In the Best Interests of the Critically Ill Child?

Abstract

Law's processes are likely always to be needed when particularly intractable conflicts arise in relation to the care of a critically ill child like Charlie Gard. Recourse to law has its merits, but it also imposes costs, and the courts' decisions about the best interests of such children appear to suffer from uncertainty, unpredictability and insufficiency. The insufficiency arises from the courts' apparent reluctance to enter into the ethical dimensions of such cases. Presuming that such reflection is warranted, this article explores alternatives to the courts, and in particular the merits of specialist ethics support services, which appear to be on the rise in the UK. Such specialist services show promise, as they are less formal and adversarial than the courts and they appear capable of offering expert ethical advice. However, further research is needed into such services – and into generalist ethics support services – in order to gauge whether this is indeed a promising development.

INTRODUCTION

One of the few positive outcomes of the *Gard* litigation is that it re-focused public attention on “what we mean by best interests ... and how they are best served”.^[1] There is value in such public reflection, but neither a metaphoric court of public opinion,^[2] nor a literal court of law, appear to be ideal locations for determining the care of a critically ill child.

In this article, I initially explain the legal lenses through which such difficult cases are viewed and, whilst acknowledging their strengths, highlight some of the courts’ weaknesses. Recourse to law imposes various costs and the judges’ attempts to determine the best interests of children also reveal the law to be uncertain, unpredictable and insufficient. The insufficiency arises from the law’s apparent reluctance to address the ethical dimensions of such decisions.

Assuming ethical reflection is warranted, I explore the strengths and weaknesses of clinical ethics support services, focussing on the merits of investing – whether at local, regional or national levels – in specialist ethics services. Such services, which are developing in the UK, have as their core business the provision of ethical advice as to the best interests of critically ill children like Charlie Gard. They are unlikely to replace the courts in particularly intractable cases: notably, such specialist advice was available in the hospital caring for Gard, but still his case went to court. Yet, specialist ethics support shows promise and might reduce the need for legal recourse. Before advancing this hypothesis, which I hope will spur further research, I start with an outline and assessment of the law in this area.

FROM THE CLINIC TO THE COURTROOM

English law typically views cases like *Gard* through three sets of lenses, which derive from the criminal law, civil (family) law, and human rights law.

The *criminal* law comes first in this selective (non-treatment) retrospective.^[3] Homicide law has long confirmed that a fatal failure to meet a duty to care for a dependent can amount to murder or manslaughter, depending on the accused’s intention or knowledge.^[4, 5] The last pertinent trial of a

doctor was in 1981. Dr Arthur was acquitted of the attempted murder of John Pearson, a new-born with Down's syndrome. The paediatrician allegedly wrote "Parents do not wish the baby to survive. Nursing care only" and prescribed the painkiller DF118; the child died 69 hours later.[6] Summing up to the jury, Farquharson J emphasised the absence of any "special law" protecting doctors,[6 p5] but noted the lawfulness of some omissions and of symptom relief, plus the good character and motives of the defendant, who had apparently been following accepted practice.

Farquharson J was evidently uncomfortable viewing this doctor's behaviour through the criminal law lens,[3] and a different legal lens has indeed since been used. The civil – specifically *family* – law lens had actually been adopted in a ruling weeks before Farquharson J's direction, although it was not cited by him. In *Re B*, the Court of Appeal decided that life-saving surgery *was* in the "best interests" of another new-born with Down's syndrome, as it was not the case that "the life of this child is demonstrably going to be so awful that in effect the child must be condemned to die".[7]

This focus on the "best interests" or – following the Children Act 1989 – "welfare" of the critically ill child has led the way since. The 1989 Act holds that "the child's welfare shall be the court's paramount consideration".[8] Welfare is not defined, but the factors to consider when making such a judgment include "the ascertainable wishes and feelings of the child", his or her "physical, emotional and educational needs" and "any harm" he or she has suffered or is at risk of suffering.[9] Using the (synonymous[10]) welfare or best interests tests, the courts have frequently decided that life-sustaining treatment is not indicated.[11] The Court of Appeal has emphasised that the test is indeed the best interests or welfare of the child:[12, 13] references to an "intolerably" poor or "demonstrably ... awful" quality of life are not to be treated as glosses on the test.[14] Despite such warnings, the Court of Appeal has helpfully indicated the basic approach:

"The judge must decide what is in the child's best interests. In making that decision, the welfare of the child is paramount, and the judge must look at the question from the assumed point of view of the patient. There is a strong presumption in favour of a course of action which will prolong life, but that presumption is not irrebuttable. The term 'best

interests' encompasses medical, emotional, and all other welfare issues. The court must conduct a balancing exercise in which all the relevant factors are weighed and a helpful way of undertaking this exercise is to draw up a balance sheet".[15 para 87]

This statement was made in *Wyatt*, a widely-publicised and difficult case, which generated no fewer than 11 rulings.[16 p187]

By the time of *Wyatt*, a third, *human rights*, lens had been overlaid on top of the family law lens, via the Human Rights Act 1998, which effectively brought the European Convention on Human Rights directly into English law. The judges thereafter confirmed that decisions taken in the best interests of the child would not violate any of the human rights therein.[17] However, the fraught case of *Glass*, which reached the European Court of Human Rights, emphasised that parents had a right to consent to treatment, under article 8 (the right to respect for private and family life), and that appropriate efforts should be made to settle disputes – including by calling on the courts when needed.[18]

THE LIMITS OF LAW

The courts, equipped with the relevant legal principles and processes, have a legitimate role in resolving (non-)treatment disputes. Law will obviously have a view on life-or-death cases and the courts are there to settle disputes; given the magnitude of some of the disagreements, which involved fistfights between family members and healthcare staff in *Glass*,[19] this sort of external – and authoritative – judgment seems appropriate. Perhaps, like *Glass*, *Wyatt* and the more recent case of *King*,[20] *Gard* was also a case that rightly landed in court. The courts are not overwhelmed here,[21 p207] so maybe all is as it should be. Yet, whether a court is indeed the best place to resolve such dilemmas is questionable.

Recourse to law imposes various costs on the parties and others. First, there are financial costs to the health service and, by extension, other patients: a PICU bed reportedly costs more than £2,000 per day.[22, 23] Secondly, there are the legal costs, which are not necessarily covered by Legal

Aid.[24 para 17] Thirdly, legal action can be stressful and distressing for the parties, particularly given law's adversarial win-or-lose mentality. Meller and Barclay point to *Wyatt*, which

“ended in a lose-lose-lose situation: an embittered and fragmented family, a child in foster care and six-figure costs for the hospital trust. The medical staff were left feeling battered and bruised and there was no real closure to this tragic case”. [25 p620]

Finally, although High Court judges are available at any hour, proceedings will typically take time, which could come at the expense of the child's interests.

This, of course, assumes that we can ascertain where the best interests of a child lie. Unfortunately, the law informing (and making) such determinations is uncertain, unpredictable, and arguably insufficient. First, the law here falls short of issuing the clear and consistent action-guiding rules required of a functioning legal system.[26] The rule initially appears clear: the welfare or best interests of the child is the paramount concern. However, the rule is also opaque: the factors guiding such a determination are only enumerated, as opposed to elaborated, with decisions taken on a case-by-case basis.[27] The judges enjoy considerable discretion,[28] and apparently similar cases have resulted in different outcomes.[11] Such flexibility might mean the law is commendably pluralistic – but the resultant uncertainty also reveals the “greatest weakness” of the standard.[29 p173]

Uncertainty means, secondly, that the law is unpredictable. Certainly, some trends are detectable: for example, the children of Jehovah's witnesses will typically be transfused despite their parents' objections,[30, 31] and, more generally, doctors' views will usually trump those of parents.[11 p89] However, the latter does not always hold true.[32]

Finally, the law in this area appears insufficient. These are “cases of ethical complexity”. [25 p619] Some judges acknowledge and engage with these dimensions,[33] but others are reluctant to do so (at least, openly),[34 p969] with Montgomery complaining of the resultant “de-moralisation” of healthcare law.[35] Perhaps law can only provide minimal standards,[36] but the ethical dimensions arguably should be aired and, if possible, resolved.

FROM THE COURTROOM (BACK) TO THE CLINIC

The law, therefore, has its limits. Commenting on *Wyatt*, Brazier noted that adjudication might “exacerbate a tragedy nature created. But is there any alternative?”[37] Three alternatives come to mind, each of which has its strengths, but also its weaknesses.

A first alternative points to prevention. Birchley’s study found professionals to be reluctant to approach the courts,[38] with one nurse participant stating:

“the last, last thing you want to do is go to court... if we can compromise before we get there, if we can talk to the family and we give them time to come to situations, or we may come – we may change our minds as well”.[39]

The courts and professional guidance similarly emphasise the importance of good communication and shared decision-making,[12, 40] which might deter disputes from arising or escalating. Training professionals in communication skills, as well as in how to recognise, understand and manage conflict,[41] might therefore help avoid or quell disputes.

Yet, further alternatives will be needed if disputes nevertheless arise. A second alternative found support in *Gard*, wherein Francis J offered the

“clear view that mediation should be attempted in all cases such as this one even if all that it does is achieve a greater understanding by the parties of each other’s positions”.[24 para 20]

The use of mediation in these cases has also been promoted by Meller and Barclay,[25] and was commended in a Nuffield Council on Bioethics report, which recommended research into its possible benefits.[42 para 8.56–8.62 and 9.39]

Mediation might well avoid some of the costs of legal proceedings and could potentially enhance understanding and trust between the participants, so further exploration of its possible benefits certainly seems merited. However, like the courts, mediation will generate case-specific outcomes, which will not necessarily attend sufficiently to the complex ethical issues. Assuming these ethical

dimensions should be addressed, a further alternative is required, and it is on this I wish to focus (as distinct from, but without denying the possible benefits of, the preceding approaches).

The means to explore the ethical dimensions of ethically difficult cases already exist, typically (in the UK) taking the form of clinical ethics committees (CEC). The UK Clinical Ethics Network (UKCEN), the charity which promotes ethics support and facilitates contact between CECs, describes CECs as

“multidisciplinary groups, including health professionals and lay members that aim to provide support for decision-making on ethical issues arising from the provision of patient care within NHS Trusts and other health care institutions”.^[43]

From 20 committees in 2000, there are reportedly 85 committees currently known to UKCEN.^[43]

CECs certainly appear to have their merits.^[11] First, CECs seek to provide practical advice, thus neither amounting to a mere “talking shop”, nor posing a threat to clinical autonomy. Secondly, as UKCEN noted, they are designed to be supportive: salient expertise is pooled and shared, and the processes are less formal than those of the courts. Thirdly, CECs explicitly seek to explore the ethical aspects of the particular referral. Indeed, UK CECs, like others worldwide,^[44] notably tend to be consulted about such issues as withholding or withdrawing treatment, and thus precisely the cases we have in view.^[43] Many CECs therefore have the experience – perhaps even the expertise – needed to help resolve dilemmas in this context.

CECs therefore have some advantages over courts, as they might be quicker to issue their advice, less costly (in various senses), and are more inclusive and less adversarial, at least if we accept Reiter-Theil’s observation that “the language of ethics can serve as a common language in which conflicting viewpoints can be discussed”.^[45] Furthermore, in contrast to the courts’ occasional reluctance, ethical reflection is at the heart of the CEC endeavour.

CECs therefore show promise but, like the courts, they also have their problems. First, there are problems of orientation. CECs primarily exist to support clinicians, which prompts questions about their commitment (and availability) to patients and families,^[46] their independence from the healthcare institution,^[47] and their accountability.^[48] Secondly, there are problems of operation

and process. Membership – including lay membership – is a vexed question,[49] as are qualifications, certification, competencies,[50] and deliberative frameworks.[51] McLean, a healthcare lawyer, has dubbed CECs a “due process wasteland”,[52] asking: “what and who are clinical ethics committees for?”[53] Thirdly, there are problems of impact and evaluation, prompting questions about the value and utilisation of CECs.[54]

TOWARDS SPECIALIST CLINICAL ETHICS SUPPORT

Further research into the questions surrounding CECs is undoubtedly needed, especially in the UK. Pending that, however, I hypothesise that *specialist* clinical ethics support services might offer a way forward, which could address some of the deficiencies of existing CECs, whilst also avoiding those associated with the courts.

Many existing UK CECs are generalists, accepting referrals from a range of contexts and clinical specialties. Models for more focussed support services nevertheless exist, both at the micro (local) and the macro (regional or national) levels. Some CECs already focus on particular clinical contexts, such as mental health care, palliative care, and reproductive services.[55] There are also regional and national fora: for example, the Doyle Club, for palliative care professionals, accommodates ethical reflection, while the Genethics Club,[56] established in 2001, provides “a national forum of ethics support for the profession of clinical genetics in the UK”.[57]

These sorts of micro and macro developments are also occurring in relation to the care of critically ill children. Great Ormond Street Hospital (GOSH), the Trust embroiled in the *Gard* case, has a clinical ethics service, which has been increasingly utilised since 2012, sometimes by other UK paediatric services.[58] Its co-chair also chairs the recently-formed Child Health Ethics and Law Special Interest Group (CHELSIG), “a multidisciplinary professionals group seeking to explore ethical and legal issues affecting children and their healthcare”, which, like Genethics Club, meets around the UK.[59]

Such specialist ethics support appears promising. First, the relative *informality* of ethics services, which are intended to be *supportive*, should impose fewer costs than calling on the courts, thus

saving time, money and heartache. Generalist ethics support might also have these advantages, but a specialist service has notably been commended in this regard. During its GOSH visit, the Care Quality Commission (CQC) spoke with a parent who had attended a CEC meeting, who “felt this was an appropriate course of action and said “the process was not too daunting””. [60 p106]

Secondly, the requisite *membership* of a specialised service might be more readily apparent than that of a generalist service. Various professionals – including doctors, nurses and various allied health professionals – will still be needed, but these need not cover a diverse array of clinical contexts, from conception to old age. Rather, in our context, the professional members should all have the expertise to care for sick children and their families. The necessary “lay” membership should also be apparent: at a minimum, parents of (current or previous) critically ill patients should be included.¹ Notably, GOSH’s service has such a parent as co-chair. [58 p16] Securing such input, particularly at the highest level of the service, could help to ensure that the service is oriented towards patients and families, not just clinicians.

Thirdly, and crucially, a suitably composed specialist service might be more capable than the courts or generalist ethics services of providing relevant practice-oriented *ethical advice*. Lucassen and Parker note that laws are typically general and in need of interpretation: by undertaking “detailed examination of the nuances of clinical cases”, a specialist forum like Genethics Club offers “ongoing practical support” and “clear courses of action in a particular case”. [57 pp 220, 223]

Of course, specialist services will need to be equipped to provide the relevant ethical advice. CECs need “critical teeth”, [61] and thus competencies in, and models for, ethical deliberation. Models abound worldwide, including from the UK (the Ethox (Oxford) model), [62] the US (the four principles and four quadrants approaches), [63, 64] the Netherlands (moral case deliberation), [65] Denmark (the ICU-focused “4 C’s” approach), [66] and Singapore (the “A, B, C” approach, which was developed

¹ Alongside children and young people themselves, plus academic bioethicists with experience in the relevant field.

with a British bioethicist).[67] Yet, empirical research, including in the UK, reveals that there is plurality even within a single country or indeed committee.[51, 68]

Consistency, certainty and predictability might therefore remain just as much problems for specialist services as for courts. However, the specialist focus of such a service could enhance consistency in decision-making. Although it is a contentious issue,[69] to which I will return, a specialist body might even develop and apply a sort of expertise, beyond that exhibited in generalist ethics services.

Lucassen and Parker hint at this when they suggest that “clinical genetic practice, with its focus on familial issues, remains an unusual aspect of Hospital Clinical Ethics Committee work and some committees may feel that they lack the expertise to inform practice”.[57 p221]

Applied to the current context, a specialist service seems capable, specifically, of offering expert advice on the best interests of a critically ill child. An ethics service, tasked with offering ethical advice, can therefore go beyond mere enumeration of the salient features of a particular referral, into elaboration of how the child’s best interests should be understood and effectuated.[27]

Philosophical accounts of best interests or welfare vary in their foci, looking to what people want (desire accounts), like (hedonistic accounts) or need (objective accounts).[70] By focussing on a reasonably specified range of cases, a specialist service could advance thinking in this area and – provided that due attention is given to due process – build up a body of knowledge that is capable of consistent application. According to Annas, “good ethics committees begin where the law ends”,[71] but their knowledge and experience could prove valuable both to the courts and to bioethics. As rulings in other jurisdictions indicate,[72, 73, 74] the courts might welcome the injection of specialist ethical reflection, while normative thinking about these sorts of cases might also be enhanced by the insights emanating from the crucible of experience.

Fourthly, and linked to these latter points, the provision of specialist services could help with efforts to evaluate the *impact* of ethics support. The CQC report on GOSH revealed one way of measuring impact: “The ethics service enables resolution without going to court”.[60 p106] The report noted that “Some cases were taken to court for a Judge’s decision when a consensus could not be made

through the ethics committee. These cases however were rare”. [60 p102] These observations implicitly recognise that a (specialist) ethics service might provide measurable benefits – although this is only one example, and no doubt much more evidence (of this and other sorts) would be needed to demonstrate the (positive?) effect of such services.

Indeed, these claims about the merits of a specialist ethics service all need to be explored and tested. The drawbacks of a specialist model will also need investigation. Some potential problems might afflict specialist and generalist services alike, such as those surrounding conflicts of interest, accountability, qualifications, certification and, generally, due process.² Law, of course, is fixated on due process, so there might be legal lessons (for example, on the use of “precedents”) to be learnt.[75] But specialist support services will also confront more specific questions, three of which I will mention here.

First, what should be the scope of a specialist service? And might there be risks of (and in) super-specialisation? A specialist service could focus on children, but it might more narrowly focus on (for example) children in particular age groups, children with particular conditions, or non-treatment as opposed to treatment decisions in relation to children. There is an echo here of the rise of specialised academic ethical reflection, revealed by the proliferation of “X-ethics” fields and journals. Might any narrowing of focus mean that something – such as relevant learning by analogy – will be lost?

Secondly, what should be the location – and geographical reach – of a specialist committee? Should this be nationally, regionally or locally situated? Again, something might be lost if services are too centralised or are otherwise too distanced from the place of caregiving; for example, one argument in favour of localised ethics support is that a locally-based service will have pertinent knowledge of institutional, geographical and clinical context.

² Including reporting back to participants in the referral (see [60 p106]) and ensuring there is (appropriate) transparency; my thanks to Riordan Deehan-Jackson for emphasising the last point to me.

Thirdly, specialist services force (re-)engagement with the vexed question of ethical expertise: what expertise might – or should – a specialist committee and its members be expected to have?

The case for a specialist service seems to hinge on it having relevant expertise in relation to the problems coming before it and relevant expertise in the ethical analysis thereof. Of course, questions immediately arise about what amounts to “relevant expertise”, who is “experienced” in the relevant ways and what “such problems” are (i.e. the aforementioned remit of the committee). As noted, relevantly experienced people would include those with lived experience of dealing with such problems, such as affected parents and appropriately qualified clinicians. Ethical expertise is more problematic. What sort of expertise is this, who – if anyone – possesses it, and why, in particular, should anyone listen to a clinical ethicist?[76],[77] Some bioethicists argue that moral philosophers are “experts in matters of morals”, [78 p117] but many in the field disagree.[79] Whether or not they can be considered moral(ising?) experts, bioethicists working as clinical ethicists are likely to have pertinent skills in clarifying and negotiating ethical claims, suggesting there is a case for their inclusion in specialist services.[11] However, here too we might wonder who counts as a “bioethicist” or “clinical ethicist” in the relevant sense and whether such a person(s) should have specialist knowledge of the specific problems the service will address. More generally, even if specialist services can develop and exercise a sort of expertise, they could risk becoming inappropriately insular and stuck in their ways.

Questions like these deserve further consideration. It nevertheless appears that ethics support, and specialist ethics support in particular, has its merits, including the possible avoidance of legal proceedings in cases like *Gard*.

CONCLUSION

GOSH, of course, arguably had a specialist ethics service and yet *Gard* still came to be decided in a courtroom. This reinforces the need for further research into the strengths and weaknesses of such services. Law’s processes will likely always be needed in particularly intractable cases. Yet, if

specialist ethics support services can deliver on their apparent promise, it may be – as the CQC found in relation to GOSH – that recourse to the courts will be rare. The courts, backed by well-developed processes, are there to decide when needed, but they are costly (in various senses), and their decisions about the best interests of critically ill children appear to suffer from uncertainty, unpredictability and insufficiency. Amongst the alternatives available, specialist ethics support services show particular promise, as they are less formal and adversarial than the courts and they appear capable of offering expert ethical advice. Questions nevertheless surround such services, and indeed generalist ethics support services, so further research is needed to gauge whether this sort of ethics support is indeed a promising development.

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