Disagreement, mediation, arbitration – how to resolve disputes about medical treatment

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Funding: DW and JS were supported for this work by grants from the Wellcome trust WT106587/Z/14/Z, WT 104848/Z/14/Z, WT203132/Z/16/Z. JS was also supported by the Victorian Government's Operational Infrastructure Support Program. The funders had no role in the preparation of this manuscript or the decision to submit for publication.

Contributors' statement: DW conceived of this commentary, wrote the first draft and edited the manuscript. JS designed the figure. SB and JS contributed to the analysis and to the writing of the manuscript**.**

Word count: 1000 words

On 28th May, the legal case about treatment for 23-month old Alfie Evans reached its sad conclusion when the infant died, 5 days after withdrawal of ventilation against his parents' wishes.[1] The battle was traumatic for his family and distressing for health professionals. This was the third case in the UK to have reached public attention in 18 months.[2,3]

In the wake of these damaging disputes, it is tempting wonder what might have been done differently. It is more important to look forwards. This will not be the last case of disagreement as treatment options increase and patients become more empowered. Other commentaries on these cases have examined changes to UK law,[4] or the use of tribunals rather than courts to resolve disputes.[9] Here, we outline the complementary roles of ethical analysis, mediation and arbitration and provide a schematic framework for resolving disputes (Figure).

While legal or tribunal decisions may ultimately be necessary, ethical analysis is prior. It is impossible to resolve disagreement unless there is clear understanding of its nature, source and impact. Key considerations include the anticipated length of life, the quality of that life (including whether the child is in pain) and the probability of improvement.[5] Differences of opinion may arise from disagreement about the facts or how to evaluate those facts. These have different implications, though are sometimes difficult to disentangle. Clinical ethics consultation can be valuable in helping to identify and separate out the key ethical or value considerations and options.

It is not always easy for health professionals or families to understand why they are disagreeing. The intense natural emotional response to serious illness in a child can make it hard for families (and professionals) to articulate where and why they hold a different view. Sometimes communication has broken down. This can lead to professionals and parents avoiding each other – vital discussions do not take place. Entrenched positions often follow and the interests of the child start to get lost as conflict escalates.[6] The more entrenched the dispute, the more difficult it can be to resolve without specialised support.

One option, as suggested by Justice Francis in the case of Charlie Gard, is mediation.[7] This involves a neutral, external facilitator whose role is to try to help parents and professionals reach a resolution which all are able to accept. [8] Mediation can be attempted at any stage of a disagreement but parents and professionals must have confidence in the process rather than feeling it is being imposed on them.

Where disagreement is based on different understanding of the facts, parents may not believe the medical team. It is often helpful to obtain external specialist second opinions. For external review to be genuinely valuable for families, they need to be confident of the independence of those opinions. Sometimes parents suspect their child's medical team of inviting colleagues whom they know will support their views. One possibility would be to develop a register of qualified specialists prepared to provide such opinions, which could be used by families to identify experts.

Where disagreement is based on different values, it may still be possible to find common ground and negotiate an outcome that can be accepted by all. Mediation can sometimes help parents and professionals acknowledge that the consequence of conflict has been to

shift focus away from the needs and welfare of the child. Professionals are understandably uncomfortable about involving an external mediator but they can often help to facilitate less confrontational conversation while supporting all the parties. It is important throughout this process that there is an overarching ethical framework (Figure). Mediation should not be towards mere agreement but towards an ethical outcome.

It may, however, be clear that further facts or expert opinions are not going to bridge the divide; mediation simply will not succeed in some cases. At that point, it would be wrong to assume either that doctors are right, or that parents are right. There is a need to move to arbitration.

Who should be the arbiter? At present, in the UK, as in many countries, the final arbiter is the court. The court's role is to decide what course of action would be in the child's best interests. One benefit of the legal process is the potential to impartially assess the claims of both professionals and parents, and rigorously evaluate evidence and the credibility of expert witnesses.[9] However, this process is also costly, adversarial and restrictive in scope.[10] One important reason for not providing treatment that has a very low chance of benefiting the patient is because of concern for distributive justice.[11] The court has acknowledged in previous decisions that difficult decisions need to be made about how to allocate resources, but that is not the role of the court.[12] There is a need for a separate, independent process for assessing whether treatment should be provided or not on the basis of distributive justice.[13] This may also help to identify situations when it would be reasonable to allow transfer of a child overseas (as was debated in both the Gard and Evans cases).(Figure)

It is important to put these disputes in context. First, disagreement is not the norm. Most decisions are made by professionals in partnership with families, reaching a common view. Second, disagreement is not, in itself, a bad thing. Ethically complex decisions – like those around treatment towards the end of life for a child, touch on deeply held questions of value on which there can be different reasonable views.[13] Disagreement in medicine is inevitable - conflict should not be.

What is crucial, then, is how we deal with disagreement. Whatever legal or institutional changes are made, resolution will require the commitment of professionals and the involvement of families in an ethical procedure of mediation and structured arbitration. It is imperative to address diverging views in a way that is respectful, considered, ethically informed and compassionate, without losing sight of the wellbeing of the child. That is, perhaps, one of the central ethical challenges for medicine in the 21st century.[13]

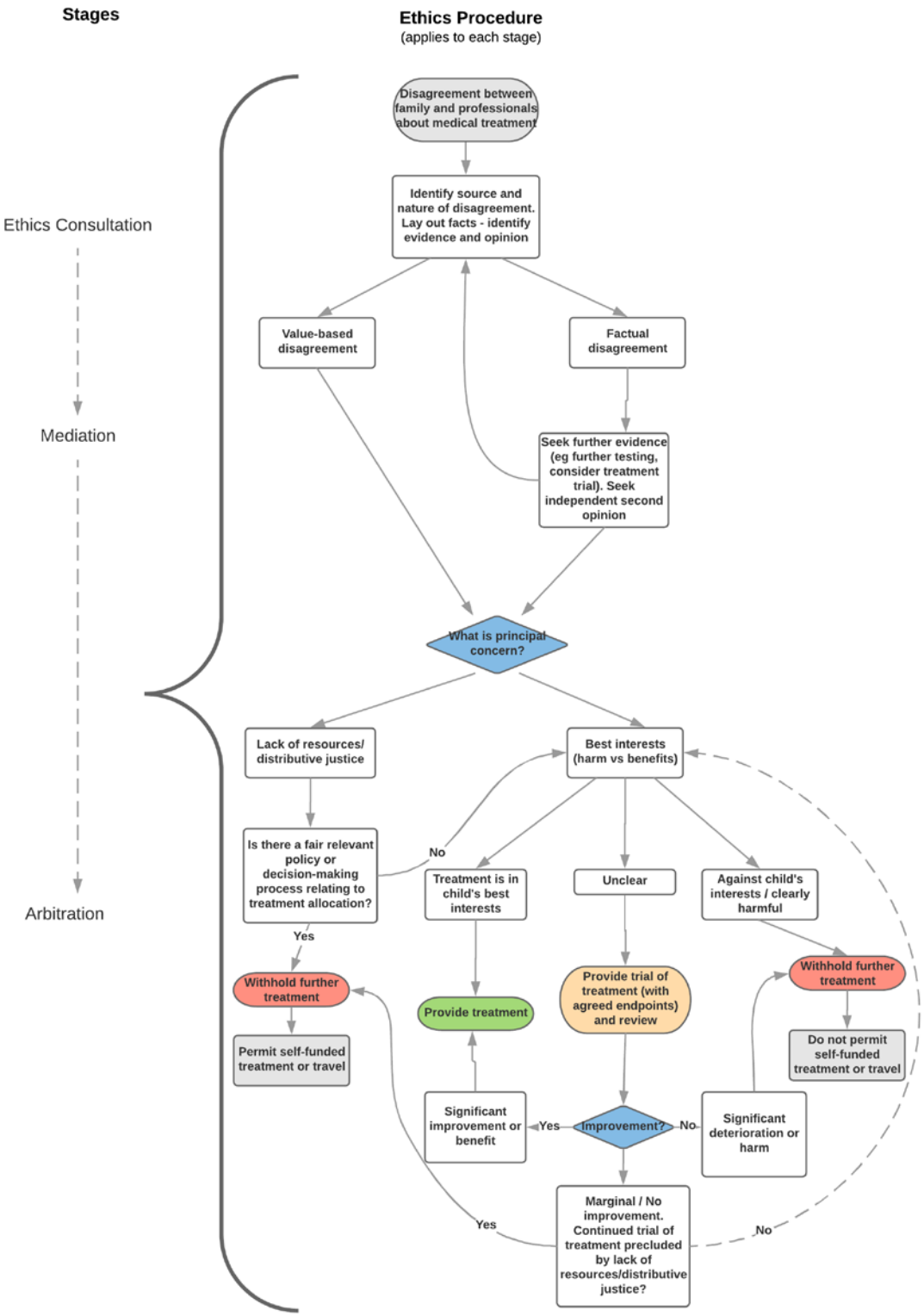

Figure: A schematic structured approach to disagreement about treatment for a child. Crucial steps in ethical analysis include the separation of factual and value-based disagreement, separation of resource from welfare considerations, and definitions of harm/benefit and best interests.

The figure relates specifically to situations where parents are requesting treatment that professionals do not support. The same principles can be applied to refusal of treatment.

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Conflict of interest statement:
Drs. Wilkinson reports grants from Wellcome Trust, during the conduct of the study. Dr Wilkinson is a member of the Ethics and Law Advisory Committee of the Royal College of Paediatrics and Child Health. (The college was not involved in any way in the preparation of this work).
He has provided external medical opinions in cases of conflict relating to medical treatment in children.
Dominic Wilkinson and Julian Savulescu have a forthcoming book relating to conflict around medical treatment in children.
Dr. Savulescu reports grants from Wellcome Trust, personal fees from Murdoch Childrens Research Institute, personal fees from Melbourne University, grants from Uehiro Foundation on Ethics and Education , during the conduct of the study; personal fees from Vermont Oxford Network, personal fees from Fertility Society Australia, outside the submitted work; .

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