VIEWPOINT

When best interests are not good enough

Hugo Gold

Children's Bioethics Centre, Royal Children's Hospital, Parkville Vic 3052
Clinical Associate Professor, University of Melbourne

Email: hugogold@tpg.com.au

Mobile: 0417115992

FAX: Leave out please

The tragic and now notorious case of infant, Charlie Gard illustrates the limitations of using the 'best interests test' as the sole or major determinant in reaching decisions in cases when doctors and parents disagree about treatment.

Generally, the test of best interest serves clinical decision making very well, accounting as it does for a balanced assessment of harms and benefits.

However, assigning value to benefits, risks and harms often involves judgements about issues such as suffering, quality of life, the significance of disability and the sanctity or "infinite value" of life. If, for whatever reason, these values are not shared, reasonable people can come to different views about what is in the child's best interests.

The problem posed by the best interest standard is that it does not easily allow for anything less. Accepting a "second best" or good enough outcome can become very difficult for both sides in a dispute.

When agreement cannot be reached, moral distress, anxiety and confusion for all parties arises. Resort to the law with its customary adversarial perspective often makes things worse. The therapeutic alliance is put at risk, trust may be lost, and the inevitable delays result in a sense of missed opportunity and moral regret. Such appears to have occurred in the case of Charlie Gard.

Charlie Gard was born with an extremely rare, genetically determined mitochondrial DNA depletion syndrome which results in progressive muscle weakness and brain damage. There is no established cure, and life expectancy is between 3 months and 12 years from the time of diagnosis. Treatment is usually symptomatic and ultimately palliative, and this was what Charlie's Great Ormond Street Hospital (GOSH) doctors advised.

Charlie's parents had requested the addition of a novel therapy with nucleoside. This request appears to have been considered by his GOSH doctors. However, whilst awaiting legal and ethical approval, Charlie's condition deteriorated to the point that brain damage became so profound that his doctors felt that no feasible benefit could result from this treatment. They informed Charlie's parents that it was now time to move to palliative care.

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The parents disagreed, based on an indication of a slim possibility of benefit from a Columbia University neurologist who had experience of treating 18 patients with similar but genetically different conditions in Spain and Italy. Charlie's parents then arranged to take Charlie to the USA for treatment. The necessary immigration permission was obtained. The hospital then applied to the family division of the UK high court to prevent Charlie's removal. Amidst great public interest both the Pope and Donald Trump offered to help him get treatment, in Rome and the USA respectively.

Parents have the right and duty to make medical (and other) decisions for their children. However, their decisions may be challenged or limited on the basis of a "best interest" threshold, particularly in the UK. Indeed, in Charlie Gard's case, Mr Justice Francis made formal declarations that "it was in Charlie's best interests" not to undergo treatment in the USA, not "in his best interest" for artificial ventilation and hydration to continue, and on the contrary, "it was in his best interest" for it to be withdrawn.

In judging treatment not to be in Charlie's best interest, the GOSH doctors, supported by the court, were influenced by the suffering caused by continuing mechanical ventilation, likely to be increased during the proposed transfer. In April the high court judge ruled that it was in Charlie's best interest for mechanical ventilation to be withdrawn, for palliative care only to be given and for Charlie not to be given nucleoside treatment. The parents appealed the judgement which was ultimately upheld both in the UK courts and the European court of human rights. In all, these proceedings took several months. The financial costs (even with pro bono help for the parents) must have been considerable, and the emotional costs to all concerned can only be imagined.

The hope for a "miracle cure" and the request for novel treatments, often "discovered" via an internet or social media search, is a natural and common parental response to situations such as Charlie's. As stated earlier, when there is uncertainty about efficacy, and particularly when values are not shared, establishing "best interests" can be difficult, confusing and the cause of much moral distress.

It is possible, however, that approaching the problem from a different standpoint could avoid much of the moral distress and confusion and allow for the development of an approach acceptable to all. When doctors' and parents' views about management cannot be reconciled, applying the principles of the Zone of Parental Discretion (ZPD)^{1,2} could allow for a mutually acceptable way forward.

The essential idea of the ZPD is to replace the need for a best interest outcome with one that is good enough to be acceptable to all. It seeks compliance with the parents' wishes, and an understanding of their goals of treatment, but is limited by the extent of probable harms.

In accordance with these principles, the response to the parents' request for the novel nucleoside therapy would be to conditionally agree. This would remove a major source of conflict by agreeing that a trial of nucleoside therapy with the aim of curing or mitigating the condition was one of the goals of treatment. The central questions would then become "What would happen to Charlie if his parents' wishes were followed? How bad would it be for him?"

The principal reason for refusing or discontinuing treatment rests on that treatment resulting in unacceptable harm in the form of increased pain or discomfort, or additional damage. Charlie's condition was so bad, and his prognosis so poor that it seems unlikely that nucleoside treatment could make it worse. It would therefore be within the ZPD.

The proposed transfer of Charlie to the USA, if it indeed was necessary, would likely cause additional pain and discomfort. This increased probability of harm may take it beyond the ZPD.

There are other relevant ethical concerns involved in considering novel treatments such as Charlie's proposed nucleoside therapy. These are not directly addressed by the ZPD principles, but underlie the conditions required to allow treatment to proceed.

Firstly, there must be a plausible or feasible rationale for the proposed treatment. Whilst assessing the evidence for the proposed nucleoside therapy is beyond the scope of this paper, it seems possibly sufficient to allow for a trial of treatment.

Secondly, it is important to recognise that the therapy is a trial. Clearly defined indicators of response and timelines need to be set, with a clear understanding that failure to respond signals cessation of this therapy.

Thirdly, the issues of equity and distributive justice may require that the cost of Charlie's novel treatment be met from non-hospital private sources. This would aim to provide for the costs directly added by proceeding with novel treatment. There should be sufficient resources to ensure that no other patients are deprived of conventional treatment, such as the availability of an ICU bed. The parents appear to have raised sufficient funds (almost \$2 million) to meet these needs, with the potential to raise further funds if required.

Therefore, at least on the assumptions above (especially if transfer to the USA was not required), it appears that each of these conditions could be satisfied. A time limited trial of treatment in accordance with the parents' request might have avoided conflict, preserved the therapeutic alliance and built trust. Moral distress might have been minimised, and the resort to the courts have been unnecessary. Under these circumstances an appropriate transfer to palliative care might have been accepted as one of the agreed goals of treatment.

A significant advantage of applying the ZPD approach is that it does not depend on a reconciliation of divergent religious, philosophical or moral beliefs about things like the meaning of suffering or the infinite value or sanctity of life. It respects the divergent views but is not dependent on them and it maintains the primary role of the parents. Conflict resolution is achieved by an acceptance of what is "good enough" rather than what is "perfect" – the perfect does not have to be the enemy of the good.

Acknowledgements

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Author/s:

Gold, H

Title:

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