D. Wilkinson & J. Savulescu

Ethics, Conflict and Medical Treatment for Children: From Disagreement to Dissensus

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by Chiara Innorta

Medical ethics is characterized by various arguments which are the underpinnings of moral views. However, these arguments are frequently incapable of solving bioethical problems, resulting in a clear-cut opposition between different views. Another fundamental aspect is, therefore, disagreement, which is, however, labelled with a negative connotation. When disagreement persists too long, it is often described as a sign of uncertainty and failure. Disagreement cannot be solved, without court intervention. In these circumstances, only a futile consensus is obtained and disagreement is apparently smoothed over. Savulescu and Wilkinson have experienced personally, through a complex story of a seriously ill child, the importance of giving more attention to disagreement in our society and in debates that can arise. The book is an attempt to appreciate the value of disagreement, especially in medical fields, in which possibilities of treatment are expanded by technological progress. The core idea is that we should be able to recognize the boundaries of reasonable disagreement to solve disputes without requiring all sides to agree on value-based decisions.

The *first section* starts from the breaking point, namely the *Disagreement*, which is also the title. It proposes an overview of *the Gard case*, which is the real case that inspired the book and the dialogue between the authors. There is a recap of the case, which can be summarized as follows. Charlie Gard was born in London in 2016. His parents quickly recognized that their baby was born only apparently in good health. When Charlie was taken to Great Ormond Street Hospital (GOSH) doctors discovered that he was born with a rare genetic disorder. At first, the medical staff of the GOSH, in agreement with Charlie's parents and starting from their request, decided to use an experimental treatment. Nevertheless, Charlie's condition worsened and the GOSH was no longer in favour of proceeding. However, Charlie's parents disagreed completely with the doctors' point of view. They activated a crowd-funding campaign to finance experimental treatment, which would allow them to pay for it. The GOSH requested the High Court to override the parents' decision. In a tense climate, in which the public opinion took both sides, the parents finally accepted the deci-

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sion of judge to withdraw life-sustaining treatment. The Court based the decision on the principle of the *best interest of the child*. Instead, the parents' lawyers appealed to the *harm threshold*, included in the *Children Act*, invoking a leeway of action in parenthood, as happens in ordinary life. The parents' wishes should be overridden only if it consists of a harmful behaviour towards the child. The opposition between the best interest standard and the harm threshold emerged with Diekema's paper (Diekema 2004), which popularized Mill's harm principle as a decision-making standard for children.

The *second section* gets to the heart of *moral issues* that led to disagreement. This part is entitled *Agreement* because the authors, despite the difference of views, try to reach areas of common ground. The topics from which disagreement arise are: *futility*, *best interests*, *resources*, *research* and *parents*. It is stated that the concept of futility in the Gard case is unhelpful. It is difficult to agree about the definition of this term. Even though it was possible, Truog states that the most frequent criticism is that despite the semblance of objectivity, there is the general idea that a futile treatment is subjective and based on the values of doctors (Truog et al. 1992). Hence, the doctors should be able to explain more clearly to the families the reasons why the treatment is judged to be medically inappropriate (Wilkinson & Savulescu 2011). There is agreed opinion to indicate a treatment as futile if no chance of benefit is possible. However, in the majority of cases, there is some degree of benefit although it is difficult to say how much it must be to proceed.

First of all, treatment should be provided if, in general, it is not harmful to the child. The decision to provide treatment is strictly connected with a balance of possible benefits against possible harms. Different reasons are at stake to decide if it is right to prolong life with medical treatment. The authors identify two main groups of reasons, deriving from a guideline for health professionals published by the UK Royal College of Paediatrics and Child Health (Larcher et al. 2015). The first included in the *limited quantity of life* category are commonly accepted by experts against providing treatment. The child's future life is too short to nurture doubts about benefits. However, when the judgment is based on the *quality of life reasons* the possibility to disagree increases. It is assumed that the quality of life decision depends on the patient's subjectivity, which is completely lacking in newborns. However, the quality of life standard is also applied for them, but what matters is not to consider it as an objective test with a single answer. Appealing to quality of life opinions leads to the attitude to opt against the treatment if it will cause the child to suffer significantly. Nevertheless, it is more problematic when the child is not suffering but is experiencing reduced benefit from life. However, the RCPCH identifies the subcategory "lack of ability to derive benefit" which includes children that may not be able to enjoy the benefits of continued life, due to the severity of their underlying condition. The doctors argue that, in these circumstances, even in the absence of demonstrable suffering, continuation of Life Support Treatment may not be in their best interests because it cannot provide overall benefit to them.

Even if the treatment could be a benefit for the child, the authors state that it is a moral duty to take into consideration also how resources should be distributed in order not to create inequalities. In particular, they highlight this question in the context of intensive care, in which resources are scarce and expensive. It is worth considering the authors' approach towards this topic because they add a theme that had been neglected in the Gard case in first place. Resources are relevant to decisions about intensive care because the choice of treating one patient can potentially harm one or more others by denying them lifesaving treatment. *Distributive justice* could be applied in a clearer way compared to the best interest standard. The decision would be based on a sort of comparison, which can confer more trustworthy reasons for acting in one way or another. However, decisions about how to allocate resources are controversial to manage. The exchange of opinions, in the past, between Singer and Harris is an evident proof of this. They discussed on the possibility to allocate resources applying QALYs even when the decision-maker is a rational egoist who has to choose behind Rawls's veil of ignorance (McKie et al. 1996 – Harris 1996). Although this topic was not preeminent in the Gard case, it raised a series of questions. Why did the Court decide that Charlie's parents, despite having raised the funds privately, could not move their child to the USA and put him under experimental treatment? This implied occupying the ICU bed for one patient unnecessarily, when it would have been more useful to have it available for other patients. In hindsight, bearing in mind legal costs, would it not have been wiser to proceed with the treatment for a limited period?

However, the discussion about resources becomes more complicated for experimental treatment, due to the uncertainty about the benefit it will bring. The authors state that the chief limit of research consists of *balancing* the potential *gains* compared to *risks*. The risk of harm is a strict standard, which fixes severe boundaries to what could be deemed ethically permissible in experimental treatments. However, it is not completely clear in which way we should apply this limit. Probably, Charlie was unable to feel pain and the experimental treatment could not have worsened his condition. With the Gard case, it became necessary to ask when it is permissible to proceed with medical research, even just for the sake of knowledge, knowing that the patient will not be able to benefit, but neither harmed. Another restriction for research is represented by evidence. The idea of *equipoise* states that evidence should not favour new experimental intervention or the current standard of care. The authors argue that both doctors and judges, to whom crucial choices are delegated, should possess the quality that Rawls assigns to the *competent judges*: the ability to find reasons for or against a position, an open mind, the skill to overcome one's own prejudices and others (Rawls 1951). Indeed, they should be those persons most likely to make correct decisions.

Finally, this section ends by dealing with parental role. There is a sort of overlap between the *parental autonomy* and the autonomy for adult patients. We agree to give parents the right to decide because the well-being of their child is at stake. However, there are cases in which the parental decision can be against the child's interest. The authors are careful to give the proper importance to the parental role. The fundamental premise is that we should, in general, allow parents to make decisions about treatment for a child, within reasonable bounds. If the parental view is acceptable, it is wrong to impose doctors' preference on them, even though it could be more embraceable. This model is proposed by ethicist Lynn Gillam (Gillam 2016), under the name of *zone of parental discretion*. Nevertheless, how wide should this area be? Disagreement increases precisely in trying to answer this question.

The *third section*, entitled *Agreeing to Disagree*, contains the original topic of the book. What emerged from previous chapters is that it is doubtful that an objective test can always suggest what would be best for a child. Even though there are some situations where one course of action clearly represents the better option, in other cases there will be *reasonable disagreement*. The idea of *reasonable disagreement* used by the authors derive from Rawls's thought (Rawls 1993). Rawls claims that people, through the free exercise of their reason, will invariably come to subscribe to a variety of different but, nonetheless, reasonable perspectives. Reasonable disagreement can be explained by such factors as the indeterminacy of many of our moral concepts. The only way to promote it consists of examining whether there are different courses of action over which parents/families may choose. When we deal with ethically complex decisions, agreement is a too stringent outcome. The authors coined a new definition, namely *reasonable dissensus*, both for limiting treatment as well as for providing medical treatment. The underpinning of this normative model is the philosophical idea of *pluralism*, which is strongly distinguished from relativism. Pluralism, in addition to accepting more than one view, defends the idea that there are as many correct viewpoints as incorrect ones.

The book is pervaded by one fundamental question: *Can we agree to disagree?* Wilkinson and Savulescu use the Gard case as a paradigm case of contemporary medical/family disagreement about the treatment. They broaden the moral discussion showing that there are limitations to existing ways of responding to disagreement. Especially because it is inevitable to foresee more complicated scenario. Hence, the aim of the book is to build awareness of the necessity to incorporate disagreement into bioethical debate, which is a relevant intuition to examine in depth. This is the first attempt to achieve this outcome. Indeed, in the appendixes there is the explanation of the authors' viewpoints, which, although different, coexist and interact with each other.

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