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Book review

Medical Decision-Making on Behalf of Young Children edited by Imogen Goold, Cressida Auckland and Jonathan Herring*

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The recent cases of Charlie Gard, Alfie Evans and Tafida Raqeeb and their prominence in the mainstream media have promoted international debate about the role of parents in decisions pertaining to the provision or non-provision of life-sustaining treatment by healthcare professionals. This involves situations where everyone believed that what *they* wanted was in the child's *best interests*. Everybody had an opinion on these cases – from the Pope, to the next-door neighbour, from the medical professional working in the hospital in question to the medical lawyer charged with arguing for or against a particular position. These opinions spanned all extremities of thought and included chastisement of parents for daring to act against medical advice and repudiation of the same healthcare teams for advocating action against the parents' wishes. The final arbitrator in these cases was not public opinion or medical judgement or parental desire. The final decision-maker was the court. English law proclaims that, in these disputes between parents and doctors, courts have the authority to make the ultimate decision, based on their perception of what is in the child's best interests. That is the backdrop to this edited collection. Cases such as these are not easy to resolve. It is, I believe, fair to say that the best interests standard can never be wholly objective. At the end of the day, these decisions have a profound impact upon the lives of real human beings, and I am convinced that any decision-maker who reads this book will be in a better place to make a balanced and truly informed decision.

Imogen Goold, Cressida Auckland and Jonathan Herring have succeeded in producing a book that maps the approaches taken to decision-making on behalf of young children in diverse and differing jurisdictions. The book considers the following contexts: Belgium, Scotland, Switzerland, Hong Kong, China, Mexico, the United States, Israel, England and Wales, Singapore, Malaysia, Chile, Sweden, Ireland, Canada, France, South Africa, Botswana, Spain, Peru, Argentina, Norway, Australia, Thailand and Greece. This is no small task! A number of issues are teased out, including community responsibility, individual rights and cultural competence, as well as the role of the decision-maker and normative debate in relation to the standard of best interests.

In the 'Introduction' to this book, Goold et al state that the volume has two aims: (1) 'it seeks to examine the legal position of other jurisdictions and to explore whether

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situations have arisen elsewhere and how the courts in other countries have responded to them'; and (2) it critically appraises the current law.[1] They claim that '[i]t is hoped that the experiences of other countries will provide a lens through which to evaluate the approach of the English courts, and to inform the UK's approach to navigating the issue'.[2] They recognise that considerable debate exists in relation to how the interests and rights of the child are balanced with the 'responsibilities and authority of the parents; the role of medical professionals in such disputes; and the extent to which it is legitimate for the courts to intervene in private, familial decisions'.[3] Goold et al argue that the book offers a 'framework' for assessing how English law should respond to these disagreements. It seeks to act as an informative aid for readers in order to enhance their perspectives on the interjurisdictional approaches taken.

The book paints a picture of best interests that is not a linear, one-dimensional one. Rather, different authors show that best interests can be interpreted in different ways, often in line with cultural knowledge and practice. For example, Ben Gray argues that 'there is no such thing as the objective best interests of the child' and, instead of applying a best interests test, the notion of 'cultural competence' ought to be applied.[4] He argues that different interpretations of best interests highlight 'the absence of a common morality', and, if we accept that no such commonality exists, then the views of doctors, bioethicists and judges are actually just 'the assessment of experienced and wise people of what they think the right thing to do is'.[5] He says that this does not mean that their view does not count, but that their opinion is based on their 'cultural background' – a form of 'unconscious bias'.[6] The book brings an informed energy to debates about the best interests of children that have captured the human imagination. Having read the book, we know more about the authority of parents and their ability to arbitrate for the child; we understand that there are cultural limitations to this authority; we have learned much about medical interventions in clinically different contexts; and we understand that harm can befall a child, not only through illness and the protection from illness, but also through over-intervention when there is little hope that that intervention can sustain a quality of life that is in the best interests of the child.

Discussion in the book pertaining to medical decision-making on behalf of young children is grounded in bioethics. Rosalind McDougall develops bioethical debate relating to best interests and discusses whether a different principle (the 'harm threshold') should replace the best interests test. Much of the literature in bioethics concerns this clash between best interests and the harm threshold. However, McDougall argues that an inadequate focus has been placed on the role of the decision-maker.[7] In her view, there is a failure to consider the relationship between *who* ('who is the appropriate decision-maker when there is an entrenched disagreement between doctors and parents about a child's medical treatment?') and *how* ('how should decisions be made?').[8] Thus, she argues that there is a need to move beyond the 'best interests' versus 'harm threshold' arguments. She says that further clarity is required in relation to these issues and that '[i]f we are clear

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[1] Imogen Goold, Cressida Auckland and Jonathan Herring (eds), *Medical Decision-Making on Behalf of Young Children* (Hart 2020) 3–4.

[2] Ibid 4.

[3] Ibid 4.

[4] Ibid 325.

[5] Ibid 329.

[6] Ibid 329, 331–333.

[7] Ibid 6.

[8] Ibid 7.

about the role of the decision-maker and the nature of the question that the decision-maker is answering, we can more deftly employ the most appropriate conceptual tool or tools'.[9] She also argues that conceptual creativity is required.[10] This bioethical discussion provides an ethical lens by which and through which many of the subjects discussed in subsequent chapters relating to the specific jurisdictions can be viewed.

A review such as this could not possibly summarise all of the approaches taken in the countries explored: there are, however, a number of themes that emerge throughout the book, including rights as they apply to parents and children and the role of legal systems in responding to ethical dilemmas surrounding the application of such rights. Cultural competence is identified as a motif within some jurisdictions. The book lays bare the legal and cultural differences that apply to medical decision-making across a number of jurisdictions. The key question of 'Who decides?' finds voice within this book in a range of challenging medical contexts, including end-of-life care and the context of critically ill children.

The book weaves together the complexities that apply when there is contention about parental authority, as it applies in culturally diverse contexts. Goold and Auckland conclude that resolution to contention lies in bringing together all the voices within all the contentious debates in 'a manner aimed at informed and culturally sensitive consensus building'.[11] They contend that the journey towards resolution includes recognising the differences within communities, within cultures, within the way in which the best interests of the child can mean different things in different situations. This argument is well made in the book and is founded on a rich vein of authority and an insightful analysis of contentious contexts in a range of jurisdictions.

Paradoxically, a primary strength of the book may also be perceived to be a weakness: each of the contributors keeps very clearly to the assigned remit. There is great certainty in each chapter in terms of its depiction of a particular aspect of decision-making on behalf of children. This adds clarity to the book, and those who wish to be immersed in this very interesting topic will find depth of research and richness of debate therein. However, the reader who likes to meander in and out of a key topic and to be swayed by tangential arguments and pathways that intersect key messages, and sometimes detract attention from them, will not, perhaps, be entranced by the almost clinical attention afforded by all contributors to the key debates. To be honest, there is a certain tedium, occasionally, attached to the faultless rigour that applies to reading similar material within different contexts from, of course, differing and interesting perspectives. That is a small flaw, if, indeed, a flaw it is because, in my view, the aims of the book are well met, the objectives are achieved and conclusions made are fascinating and purposeful and, if applied, have the potential to amend contentious practice.

I urge anyone who is interested in medical law and ethics to read this book. The way in which the law is presented and analysed through different jurisdictional vistas is a *tour de force*. You will not be disappointed. You will walk away from this book feeling that you have learned something important about the application of law at an interjurisdictional level. You will jump from the connection between parental decision-making and the manifestation of religious belief in Switzerland to the role of Confucian ethics in Hong Kong. You will be intrigued by the fact that 'the courts implicitly deem children to be

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[9] Ibid 16.

[10] Ibid 16.

[11] Ibid 359.

property that parents co-own' in China.[12] You will learn about the relevance of sanctity of human life in Israel and the Latin American context in Chile. You will read about constitutional restraints in Canada and preserving family relationships in Botswana. All the other intriguing issues that are found in the paragraphs and pages of this wonderful book will be a source of interest and knowledge to the astute reader.

It is hard to conceive of a more onerous responsibility than that of making medical decisions on behalf of young children. Think of the anguish of parents confronted with medical opinion that asserts that the best step for their beloved child is removal of life-sustaining treatment. These parents have lived through every joyful, painful and often sickness-filled moment of their precious child's life. In the main, they want and need to sustain that life for even a few moments longer, no matter, sometimes, at what cost. Think of the medical consultant, the oncologist who has approved and supervised the most invasive and painful medical procedures that were initially aimed at improving and extending life, but now that consultant comes to the sad realisation that these treatments have little medical benefit and, in fact, will cause pain and suffering to the child. Think of the judge in the court of law who has to bring wisdom to bear upon these competing stances and hold fast to the idea that the child and the best interests of the child are what is paramount. This book has provided us with a window seat to the evolving medico-legal and familial drama that applies to these sad and emotionally challenging multijurisdictional cases.

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[12] Ibid 71.