# Legal and Cultural Differences in Medical Decision-Making on behalf of Very Young Children

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This collection brings together analyses of disputes between parents and doctors over the treatment of seriously ill young children from more than twenty-five jurisdictions across six continents. While it is impossible to do justice to all of the themes or patterns that emerge from the contributors in this book, in this chapter, we hope to draw out some of the key themes, and to contextualise these within the social and cultural background of the countries discussed. We begin by exploring the reasons for the lack of reported case law in many of the jurisdictions, which may be explained both by some countries' values being less likely to give rise to conflict in the first place, and by the existence of alternative mechanisms for resolving such disputes which avoid an adversarial court process. We go onto consider how the role of parents in such decisions are conceptualised, and the differing limits placed of parental authority in the countries examined, with different thresholds to be met before the court can become involved and override a parent's decision. Finally we examine differences in how the courts in different countries are applying common standards such as 'best interests', and the challenges they face in doing so.

## A. Lack of case law

Writing in a jurisdiction where there is regular, high-profile and highly fraught litigation on these issues, one very notable feature from our perspective was the reported *lack* of cases coming to court in many jurisdictions.[1] Indeed, some contributors reported that there were few if any notable cases involving disputes between parents and medical practitioners that ended up requiring court intervention to resolve them. England and Wales stood apart as a jurisdiction in which conflicts between doctors and parents regularly find their way to court in a manner quite alien to jurisdictions, to such an extent that in some there is not even the mechanism for bringing disputes before the court. For example, there are no legislative provisions to that directly regulate parental consent to medical treatment of children in Botswana at all, which Admark Moyo suggests partly explains the scarcity of case law on the

[1] Contributors from Greece, Hong Kong, Scotland, Botswana, Sweden and Ireland, amongst others, noted that is rare (in some cases almost to the point of no litigation at all) for such disputes to be taken before the courts.

subject.[2] Pernilla Leviner, writing on the Swedish approach, made similar observations, noting

> The simple answer to these questions is that we really do not know much more than the little anecdotal information that health care providers relate. No similar cases have been tried in a Swedish court and as will become clear in this chapter, it is also unlikely that such cases would be brought to court due to the lack of such mechanisms in our legal system.[3]

Only Australia and the United States appeared to have similar levels of judicial treatment of such conflicts.

This naturally poses the question of why there should be such differences, the answer to which is offered to some degree by the chapters in this collection. While some regional trends can be discerned, other explanations are quite jurisdiction specific. Nonetheless two explanations for the differing levels of litigation can, broadly speaking, be discerned, which will be examined in the following sections. Firstly, disputes of this kind may be less likely to arise in the first place because the cultural context of the jurisdiction is less likely to give rise to conflict. Secondly, even if disputes do arise, the onus (either culturally or legally) of some jurisdictions is on other mechanisms for resolving it, rather than relying on adversarial legal system as in England and Wales.

### i. Lower levels of conflict

Explanations for this absence of litigation often revealed much about how background cultural and social context shapes relationships between lay people, medics and the state. We might speculate that the level of value-pluralism varies between jurisdictions, and where there is greater cultural homogeneity, and arguably a higher chance of shared values, then there is less likelihood of conflict over the right course of action for a child, and so such disputes are less likely to emerge in the first place. Admark Moyo makes this observation in regard to Botswana, where he suggests that the presence of only one major ethnic group (the Tswana), combines with "the socialisation of citizens along communitarian lines" to leave only "limited room for the clash of diverse values". Hence he suggests, "it could be that the prevailing uniform value system limits the possibility of conflicts between parents

[2] A Moyo, 'Parental Responsibility and Medical Decision-Making in Southern Africa: A Comparative Analysis of the Laws Governing Parental Consent to Children's Medical Treatment and Surgical Operations in South Africa and Botswana', in this book.
[3] P Leviner, 'Who Has the Final Word? On Trust and Legal Uncertainty Within the Swedish Health Care System', in this book.

themselves".[4] By contrast, value-pluralism is a feature of countries such England and Wales and the United States, as well as much stronger commitment to individualism and individual liberty, and this might go some way to explaining the levels of conflict in those jurisdictions. This tendency is likely exacerbated by the relative lack of focus on communal or collaborative decision-making in the adversarial court system once the matter passes beyond a hospital's own mechanisms for mediating conflicts between doctors and parents.

A more clearly discernable correlation that emerges from the chapters in this collection is that highly communal cultures often had low levels of litigation. For example, both contributors from African countries noted a communitarian approach to decision-making in the jurisdictions considered which, coupled with a commitment to resolving disputes by avoiding conflict, meant disputes rarely found their way into the courts. This was bolstered by the central position occupied by the family in some African countries. For example, as Moyo comments, both South Africa and Botswana

> are largely inhabited by ethnic groups that are predominantly communitarian and therefore view children as an integral or inseparable part of the family. Communitarian cultures and societies pose a serious challenge to the individualistic nature of rights, particularly those of children. Children's rights potentially clash with African cultural ideology because the latter emphasises collectivism, reciprocal duties of support and restraint on individual rights. Hence, the preservation of group identity is thought to be in the interests of the child and the interests of the family. There is an attempt to limit conflict at all costs, even though this may mean a violation of children's rights to medical treatment and access to health care services.[5]

Samuel Ujewe suggests that this communitarianism is a feature of the "African ethics outlook" wherein

> communal responsibility takes centre stage and the moral frame of reference is underpinned by the network of communal relationships. The ethic of communal responsibility emphasises a preoccupation with the wellbeing of whole communities or societies; not simply of individuals constituting them. It motivates individual members to seek the good of the community or society as a whole, in virtue of which they also seek their own good and build a firm basis for a sustained wellbeing.

[4] SJ Ujewe. 'Making Decisions for Children in Healthcare and Medical Research: African Communal Responsibility or Individual Rights?', in this book.
[5] ibid.

Consequently, he explains, "[r]restoring the health of the family member, especially if they are a child:…cannot be a matter for doctor and patient alone: it demands the participation of the entire community"[6]

Sweden, too, showed a commitment to consensus-building, but the foundation for this differed somewhat. Leviner explains that in Sweden, the focus is on the responsibility of the healthcare provider, rather than on individual rights, but that this sits against a background of a "high degree of trust" of individuals for one another and for public institutions.[7]

How central the role of the family played in a culture also affected levels of litigation. High levels of litigation were reported in England and Wales, the United States and Australia, all of which give cultural (as well as legal) prominence to individualism. By contrast, setting aside Sweden (where the individual is very much the key figure), for the most part, lower levels of litigation correlated with the family unit holding a vital place in the jurisdiction's culture. Numerous contributors discussed the role of family in making such decisions, and this often explained the lack of cases, albeit for different reasons.

Thailand, Peru and China are countries which attach great importance to the family culturally, and this manifests itself as 'parental authoritarianism', where the parents' decision about a child generally holds sway, even where medical professionals disagree. As Thitinant Tengaumnuay argues, in Thailand this explains the lack of judicial intervention in the parents' decision-making, and the lack of "legal provisions setting particular checks or reviews on parental decisions concerning their children's medical treatment".[8] Thai doctors often remain passive in the face of parental decisions with which they do not agree and in the view of Tengaumanuay "would not provide health treatment that opposes the parents' decision". Similarly in China, medics largely defer to parental decisions, hence avoiding court battles, because those decisions are, as Ding Chunyan argues,

> often made based on familism or 'family-paternalism'"…where "in making such decisions, parents not only consider the interests of the child but also those of the family as a whole, including financial burdens of the family, the interests of other children in

[6] ibid., quoting from B. Bujo, *Foundations of an African Ethic: Beyond the Universal Claims of Western Morality* (New York, The Crossroad Publishing Company, 2001), 46-47.
[7] Leviner (n 3).
[8] T Tengaumnuay, 'Parental Authoritarianism and Medical Decision-Making in Thailand: The Need for Limiting the Parental Authority', in this book and D Chunyan, 'Medical Decision-Making on Behalf of Children in China: A Multi-dimensional Analysis of Parental Authoritarianism', in this book.

> the family, the impact on the career of adult family members, the implications for family life etc".[9]

She goes on to explain that "Chinese parents often see their children as property that they own, and this view is even shared by judges in adjudication", and this results in parents having a high degree of control in situations where there would otherwise be conflict and disagreement. Medics tend to yield rather than opposing parental wishes. Similarly in Peru, Paula Siverino Bavio reported that doctors tend to avoid conflict and defer to parental desires to continue treatment for fear of being regarded as having illegally failed to treat. This, she suggests, has led to medical staff practising 'defensive medicine'.[10]

In some jurisdictions, the primacy of the family in such decisions is protected via its legal provisions, which likely has an effect on how these disputes proceed in practice. In addition to Thailand noted above, where the doctor does not have any legal standing to bring a case to court if they disagree with the parents assessment of their best interests,[11] in Belgium, the medical professionals "must in principle respect the decision of the parents" and where parents refuse a proposed treatment, the physician may face prosecution for performing it. It is also the case that a physician who refuses to perform a treatment that the parents request, particularly one that may potentially prolong or save life, may face criminal prosecution (as well as potential civil liability and sanctions). Only in exceptional cases where parents refuse a life-saving therapy can a doctor fail to accept that decision.[12] In Ireland meanwhile, the centrality of the family is recognised through its constitutional provisions. The Irish Constitution declares the family to be

> the natural primary and fundamental unit group of Society, and as a moral institution possessing inalienable and imprescriptible rights, antecedent and superior to all positive law[13]

and this, explain John Lombard and Lydia Bracken, creates a presumption that the best interests of the child will be met by the marital family. This presumption can be displaced only in 'exceptional cases', with the result that in practice, parental decisions are generally

[9] D Chunyan, 'Medical Decision-Making on Behalf of Children in China: A Multi-dimensional Analysis of Parental Authoritarianism', in this book.
[10] P Siverino, 'Who Decides the Best Interests of the Child in the End-of-Life Process? A Look at the Peruvian and Argentine Reality', in this book.
[11] Tengaumunauy (n 8).
[12] I Boone, 'Parental Rights, Best Interests and Significant Harm: Medical Deci-sion-Making on Behalf of Children in Belgium', in this book.
[13] Art 41.1.1° of the Irish Constitution.

followed. As Lombard and Bracken comment, the strong protection of parental decision-making

> means that where there is a dispute between the medical profession and the parents as to the treatment of the child, the medical profession will often have little choice but to bow to the parent's decision or to seek judicial intervention. In line with the constitutional framework, court orders are only sought in the most serious of cases, where there is a dispute as to the best course of action for the child.[14]

It is important to note, however, that this presumption applies only where the parents are *married*: where the child's parents are unmarried, the primary consideration is the child's best interests, rather than the parents' marital status.

The centrality of family has different implications in other jurisdictions. According to Ujewe, "[i]n African settings, the family is recognised as a fundamental and highly valued institution", yet as we have seen this leads to a communal, consensus-driven approach, rather than parental authoritarianism.[15] Where in Chinese and Thai culture, this family-centrism affords the family final decision-making power to achieve what is best for the family, in African nations such as South Africa, Moyo suggests it avoids conflict (and hence litigation) because

> the individual rights or interests of the child and those of the family are symbiotic and inseparably interwoven. This approach stands in sharp contrast to international and domestic laws that emphasise the primacy of the child's rights and interests. Given that the child is not seen as an atomistic individual living outside the realm of relationships with others, the possibility of conflicts between parental interests and children's interests are limited.[16]

Daisy Cheung describes the approach in Hong Kong, with its obviously strong Chinese influences, as a 'moderate' familist position. While the family does take a central role in decision-making in Hong Kong, and decisions are taken by the family as a whole, the emphasis is on 'harmonious interdependence'. "The preferred arrangement in Hong Kong is," she explains, "for the patient and the family to make a decision as one unit". The key role of family discourages physicians from challenging decisions made by the family, particularly given the desire to promote and maintain familial harmony and integrity.[17]

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[14] J Lombard and L Bracken,'Medical Decision-Making on Behalf of Children in Ireland', in this book.
[15] Ujewe (n 4).
[16] Moyo (n 2).
[17] D Cheung, 'Medical Decision-Making on Behalf of Minors: The Hong Kong Context', in this book.

In other jurisdictions meanwhile, contributors explained that there was little conflict because of a tendency for parents to defer to the opinions of the medical profession. In Spain for example, Monica Navarro-Michel suggests there have been no cases of parents challenging physicians in court because of the very high degree of respect and trust that physicians enjoy there.[18] A tendency for parents to defer to medical professionals in Malaysia, was similarly offered as an explanation for the lack of case law in this jurisdiction. Calvin Ho and Sharon Kaur comment that

> Malaysian parents may be reluctant to challenge decisions made by healthcare providers. There is some evidence that parents in most instances defer to recommendations of doctors. A 1999 study on withdrawal and limitation of life-support in paediatric intensive care at the University of Malaya Medical Centre found that families often requested paediatricians to do what was best for their children. A more recent multinational study on resuscitation decisions for extremely preterm infants reported that 72% of Malaysian respondents felt that physicians should make the final decision.[19]

That said, when parents *do* disagree with doctors, Ho and Kaur suggest that

> Healthcare providers are generally respectful of parental autonomy in deciding for their children and of familial integrity, which court intervention will disrupt. On exceptional occasions when healthcare providers do threaten to take legal action due to real concerns that their paediatric patient will suffer serious harm, our experience has been that parents have tended to relent on their decision.[20]

However, they observe that there have in fact been very few formal legal challenges to medical disagreement with the parents' wishes. They explain this by reference to the "combination of … ethics committees and complementary arrangements including the active facilitation of obtaining a second opinion and a mediation mechanism" which they suggest "appear to have been effective in preventing a disagreement from escalating into a full-scale legal battle."[21] Therefore it seems in this jurisdiction, the cultural factors cut in a number of directions, protecting familial decisions, but also supporting deference to the medical profession, combining with a system geared towards collaborative decision-making and consensus building.

Deference to the medical profession is also once again reflected in the legal position in some jurisdictions. For example, Swiss law supports deference to medical opinion, with the Federal Supreme Court of Switzerland taking the view that the medical opinion is presumptively

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[18]M Navarro-Michel, 'Young Children and Healthcare Decisions in Spain. Who Decides?', in this book.
[19] CWL Ho and S Kaur, 'Parental Rights, Best Interests and Significant Harms: Singapore and Malaysia perspectives on Medical Decision-Making on Behalf of Children', in this book.
[20] ibid.
[21] ibid.

compatible with the best interests of the child.[22] Jean-Frédéric Ménard meanwhile notes that in contrast to English law (where parents are default decision-makers), in the French system "physicians are the default decision makers" — a difference which, he argues, "has the potential to influence outcomes deeply".[23] While parents in France do have a "margin of appreciation in making decisions for their children", and their decisions can be less than optimal in the view of the medical professional before they are open to legal challenge, these decisions need to be "reasonable". Thus, Menard, notes, "French law explicitly tolerates a certain level of potential harm to the child in order to uphold parental authority", but physicians retain considerable authority where parents' decisions amount to "unreasonable obstinacy". French physicians do not require court approval to withdraw or withhold life-sustaining treatment if they conclude parents are acting with "obstinacy", and hence the margin of appreciation is actually limited more to the choice of treatment plans rather than the whole gamut of decision-making. This he concludes leaves doctors with a considerable degree of authority to withdraw care,[24] which may then affect how disputes are managed in practice.

There are a number of ways therefore in which the background cultural and social context of a country might result in fewer conflicts arising over the appropriate medical treatment of a seriously ill child. Greater homogeneity of values; a more communitarian outlook; greater cultural significance attached to the family unit, and more deference paid to medical professionals may all reduce levels of conflict between parents and doctors, which may in turn explain the sparsity of litigation in these countries.

### ii. Alternative mechanisms for dispute resolution

Even where disputes do arise, the onus (either culturally or legally) will not always be on legal avenues for resolution. Indeed in some jurisdictions, mechanisms for resolving such disputes judicially simply do not exist. In Thailand for example, even where doctors strongly disagree with the parents' view of what should be done, and consider their decision does not serve the best interests of the child

> the doctor or the healthcare service provider does not have any legal standings to bring a case to the court for judicial intervention of parental decisions. The mere thing the doctor could do if he or she disagrees with the option the parents choose for treating

[22] A Buechler, 'Parental Decisions on their Children's Medical Treatment', in this book.
[23] JF Menard, 'Offering a Reasonable Future: Withdrawal of Life-Sustaining Treatment from Infants in French Law with Illustrations from a Parisian Neonatal Resuscitation Unit', in this book.
[24] ibid.

> their children is refusing to provide the treatment as requested and providing proper advice.[25]

This, Tengaumanuay notes, stands in stark contrast to the English system, where doctors can request judicial determination of whether a treatment (or withdrawal thereof) conforms to the best interests of the child. Chinese law similarly does not establish procedural rules to facilitate dealing with conflicts where the child's best interests are clearly not being met. As Chunyan explains,

> Although the CPL provides a number of special procedures that do not involve adversarial parties, a proper procedure is lacking that enables either doctors or other relevant parties to file an action to challenge the parents' medical decision on behalf of children in China's civil procedure law.[26]

However Thailand and China are not the only jurisdictions without a clear means for conflicts to be resolved by the courts. For example, although Sweden has legal avenues by which at-risk children can be taken into care where parental care is lacking, Leviner reports that "this does not extend to a facility for medics to request intervention". Doctors simply "do not have the opportunity to petition for the authority to decide on the medical care initiatives that are to be carried out or not". She, she notes, is exacerbated by the fact that mechanisms for taking children into care cannot generally be used to manage such conflicts as the threshold for taking over parental decision-making and removing the child is very (essentially a significant risk of harm threshold). Consequently, she concludes that "to take a child into involuntary custody 'simply' to provide short-term medical care that the guardians oppose" is "questionable" and Swedish law is not adapted for conflicts between doctors and parents. This, she posits, may rest in part on the high level of trust placed in doctors, but also because it

> [aligns] with Swedish state individualism and the described mutual trust between individuals and public institutions, a 'consensus paradigm' exists, whereby authorities also have confidence that parents, with the help of government support (parental courses, etc.), should be able to make the best decisions for their children.[27]

Some jurisdictions, like Chile, Argentina and Israel, allow doctors to refer conflicts to an Ethics Committee which can determine which course of action is in the child's best interests.[28] In fact, many systems have some sort of internal hospital mechanism for managing disagreement, with varying levels of authority. In Argentina, doctors can raise the matter with the hospital ethics committee if there is a conflict, but families do not have similar recourse.

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[25] Tengaumunauy (n 8).
[26] Chunyan (n 9).
[27] Leviner (n 3).
[28] F Lathrop Gomez, 'Decisions About Their Body: Children's Rights and Parental Responsibility in Chile', in this book.

The law supports finding "independent and interdisciplinary resolution, rather than referring the matter to a judge", but "does not contemplate what happens if the conflict is between the parents and the medical team".[29] In Israel, disagreements may also be brought before the hospital's ethics committee, which has the power to make decisions in cases where the child is not dying. These committees comprise doctors, nurses, bioethicists, lawyer, social workers, psychologist, and relevant clergy. The goal of this system is to avoid conflicts being taken before the court, and to facilitate rapid decision-making that is "not subject to rigid legal procedures", according to Roy Gilbar.[30] While conflicts can in some cases also be brought before the Family Court, the involvement of an ethics committee offers a way of facilitating a less adversarial approach that enables shared decision-making rather than putting parents and medics in opposition to one another within the court system. Similarly, Switzerland reports successful resolution of conflicts within the hospital setting, where disagreements are dealt with via interdisciplinary child protection groups that promote cooperation. If disagreements cannot be resolved, doctors are still permitted to report the situation to the child protection authority. Buechler posits that given "the small number of court decisions in this area, it can be assumed that, in practice, many conflicts can be resolved within the hospital with the parents".[31]

The approach of some African jurisdictions also offers an alternative to the adversarial approach, and those that defer to one party or the other, via processes that aim to promote harmonious decision-making. As noted above, the focus in some such jurisdictions is on solidary and harmony, and this, in the view of Ujewe, motivates

> the communicative or indaba process, so that the outcome is not pre-determined by the stronger voice or actor. The final decision remains indeterminate and harmoniously reached through appreciation of the shared-responsibilities of all parties in upholding the best interests of the child.[32]

Such processes stand in contrast to rights-based decision-making, and the approach "is not viewed as a conclusive act or outcome-driven; rather, it is process-oriented and arrived at harmoniously."[33] The core principle is responsibility on the part of the community towards the health and well-being of the child. Ujewe argues that

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[29] P Siverino, 'Who decides the best interests of the child in the end-of-life process? A look at the Peruvian and Argentine reality', in this book.
[30] R Gilbar, 'Withholding and Withdrawal of Life-Prolonging Treatment from Young Children in Israel', in thi book.
[31] Buechler (n 22).
[32] Ujewe (n 4).
[33] ibid.

> it is important to gain some insight into the socio-cultural principles and values that inform decision-making processes in sub-Saharan Africa, generally speaking. The decision-making process in Charlie's case is underpinned by a social and cultural outlook embedded in Western Europe, which emphasise the value and place of individual rights and society's obligation to protect them. However, in African contexts, the emphasis is on the value of communal wellbeing and the responsibility of the community to protect the welfare of individual members. Decision-making processes in African contexts are, thus, informed by a sense of communal harmony. Accordingly, healthcare decisions are evaluated not only in terms of its potential consequences to the affected person(s), but also those who share vital relationships with them.[34]

The value of such a responsibility-led approach that aims for harmony is that it encourages governments to engage communities in dialogue and develop solutions that gain broad societal support. He points to the community engagement processes that led to the reinstatement of a previously opposed polio immunisation programme. While of course this does not directly apply in individual cases about children, there may be something to be said for jurisdictions considering more active approaches to address the kind of community feeling that ran high during the *Gard* and *Evans* cases.

These approaches can all be contrasted with Australia, the United States, Greece, England and others where the focus is primarily on legal avenues for resolution. For example, in Greece disagreements between parents is resolved by recourse to the courts, and Theodorus Trokanas posits that 'it is conceivable that the same legal path [would] be followed for disagreements between parents and the medical personnel".[35] Similarly in Botswana and South Africa, physicians may petition for judicial intervention to make a determination on which course of action is in the child's best interests, and this can, in South Africa, extend to setting aside parental consent to a procedure (such as non-therapeutic sterilization) that will promote the child's welfare.[36]

Regardless of the approach of the jurisdiction, it is clear from this collection that much can be learnt from the approaches of other countries to managing parent-doctor conflicts. One theme that came out time and again in contributions was dissatisfaction with 'murky' legal frameworks, where there was a lack of clear, principled guidance about how parent-doctor conflicts should be resolved. While supporting the communitarian approach in general, Moyo comments that jurisdictions such as Botswana can learn from those countries like South Africa that offer a clear hierarchy for decision-making.[37] Further, he argues that

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[34] Ibid.
[35] T Trokanas, 'Medical Decision-Making on Behalf of Critically-Ill Minors in Greece', in this book.
[36] Moyo (n 2).
[37] ibid.

> the rules should explicitly outline the circumstances under which parental consent to or refusal of medical treatment can either be reversed or by-passed by the courts, hospital authorities and the state, especially through the Minister responsible for health related matters.[38]

Ho and Kaur comment on Singapore and Malaysia that

> more could certainly be done to clearly set out considerations that help to identify relevant values and interests for the purposes of decision-making and communication in difficult cases. There are already some initiatives to this effect outside of Singapore and Malaysia, although not yet adapted to our local and institutional needs.[39]

Lombard and Bracken similarly make some criticism of the "fragmented and underdeveloped" nature of the legal framework in Ireland concerning parental rights in the context of medical decision-making for children. In their view,

> The constitutional provisions relating to the family give parents near-absolute discretion to make decisions for their children, which casts a shadow over permissible legislative and medical involvement. This has led to a dearth of professional guidelines for clinicians to use when parents disagree with the recommended medical intervention for their child. The Irish courts have established a clear line of jurisprudence on the appropriate approach in so-called 'exceptional' cases but cases that fall below this threshold remain in murky waters. It is clear that robust professional guidelines are needed to support the medical profession and to clarify the steps needed to ensure that the best interests of the child are maintained at all times.[40]

Others were critical of where the balance of decision-making power lay. For example, Tengaumnauy argues that conferring so much decision-making power on parents in Thailand leaves the children's welfare at stake and suggests that there is a need to establish a counterbalancing system where a balance is struck "between respecting parents 'decision and medical professionals 'opinions on the optimal treatment".[41] Others, such as Norway, concluded that in their jurisdiction greater attention needed to be paid to the assessment of the best interest of the child, with Karl Sovig suggesting that England and Wales provided an inspiration to such great consideration. In his view, the Norwegian domestic courts

> would still rely heavily on the assessment by the hospital doctors or other experts but the courts will normally be more willing to engage in a review of the best interest of the child than reviewing what can be considered as a medical sound treatment.[42]

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[38] ibid.
[39] Ho and Kaur (n 19).
[40] Lombard and Bracken (n 14).
[41] Tengaumunauy (n 8).
[42] K Sovig, 'Reviewing Medical Decisions Concerning Infants Within the Norwegian Health Care System – A Public Law Approach', in this book.

But while there is much to be said for a collaborative and harmonious approach, Leviner argues that at least in Sweden the consensus model might mask problematic measures taken to ensure agreement is achieved:

> It may be that parents are deferring to health care providers, or alternatively, that decisions on treatment is made 'in consensus' without doctors presenting other justifiable options for parents to consider. If justifiable treatment options are not presented to parents, i.e. doctors misusing their knowledge and power advantage, consent to treatment cannot be considered informed, which of course is a problem in itself. Conversely, it may also be the case that health care providers defer to the will of parents without necessarily having the best interests of the children at stake. The consensus paradigm consequently can conceal coercion that should possibly be tried legally, or a child's right to care in accordance with science and well-tested experience may stand back in situations where parents claim that their children should receive other treatment… Under the Swedish legal system today there is both the undesirable risk of concealed coercion by health care providers, where parents are simply persuaded or 'motivated very much' to defer to the doctors as to that treatment which is most appropriate and most reasonable in a difficult situation. This possibly often gives rise to such a restriction on the rights of parents and children to private and family life that it should require judicial review.[43]

This comparative analysis of these many jurisdictions offers examples and approaches from which useful lessons for improving practice might be drawn.

## B. The limits of parental authority

Another key point for comparison is how the role of the parent is conceptualised in different countries. In essentially all jurisdictions, parents have the authority to make decisions on behalf of their children. This derives from the need for someone to stand in the decision-making role for a child lacking in capacity, but in some jurisdictions it also reflects the belief that the family is best-placed to know what is in the child's interests. The parental role was almost universally conceived of as one of authority and responsibility, even though the language of rights is used in some jurisdictions. For example, in France parental authority endows parents with both rights and duties that must be exercised with a view to furthering the child's interests, and these are to be constrained if the parents put the child's health in danger.[44] In some, those parental rights are afforded legislative protection, as in Canada, where the *Charter* protects a sphere of parental rights and restrains state interventions.[45] In Canada, as in the United States, parents are presumed to be best placed to determine what is

[43] Leviner (n 3).
[44] Menard (n 23).
[45] C MacIntosh, 'Decisionally-Incapable Children and Medical Treatment Choices in Canada', in this book.

in the child's best interests.[46] In none were parental 'rights' conceived as absolute, although it emerged as we have seen that in some jurisdictions parental views will rarely be overridden.

What varied considerably between the jurisdictions examined in this collection was the *extent* of parental authority. This is so despite the fact that all (or almost all) jurisdictions considered here have ratified the United Nations Convention on the Rights of the Child (CRC)[47] and the Convention for the Protection of Human Rights and Dignity of the Human Being with regard to the application of Biology and Medicine (Convention on Human Rights and Biomedicine). In most jurisdictions, tolerance of parental discretion gives way at *some* point. The question was where this point was.

The bar is set perhaps highest in practice in China where, Chunyan reports, the courts "have never intervened in a guardian's medical decision for a child", even in cases of parental refusal of treatment for conditions that are curable. Indeed, in one widely-publicised case, of a father who refused treatment for his baby's imperforate anus, judicial intervention was not even sough even after offers to pay for and arrange the surgery were made to him. This is unsurprising given the high level of deference to familial decisions, and the lack of procedural rules for dealing with conflicts where the child's best interests are clearly not being met.

Lower bars are set in most jurisdictions, with some favouring what is often referred to as a 'significant harm' threshold. In Chile, for example, the threshold is one of risk of serious harm or death. Cameron Stewart suggests that the Australian approach proposed by Thakeray CJ "is very close in flavour to the principle of 'risk of significant harm'", suggesting as it does "primacy for parental decision-making and a preference for the court not exercising power in cases when the parental decision is clearly not incorrect or badly made."[48] Francis et al suggest the approach in the United States, in some states at least, is similar,[49] while Mexico takes a related approach. Under Mexican law parental authority to make decisions for children has been held by the Supreme Court to be limited when the rights of the child are put at risk, or their health threatened. For example, the court does try to enable parents' religious freedom, but this is limited, as in the case of blood transfusion refusals, which have been

[46] L Francis, D Diekema and J Botkin, XXX, in this book; Belgium also takes a similar view : Boone (n 12).
[47] UN-CRC of 20 November 1989.
[48] C Stewart, 'Children and Medical Decision-Making in Australia Post-Gard – a Possible Reformulation', in this book.
[49] Francis et al. (n 46).

permitted only when a feasible alternative treatment for the child has been available.[50] As we have seen, the threshold in Ireland is also high, with the court making a determination only in exceptional cases where the parents' failure in the responsibilities is likely to prejudicially affect the safety or welfare of any of their children.[51] For example, a parental refusal for their child to receive a heel prick test to screen for disorders at birth was not sufficient.

Swiss law also operates a high bar for authorizing the court to override parental wishes---serious endangerment to the child's health, although if the doctors treating the child consider that this poses a significant risk to the child's welfare, they can involve the child protection authority.[52] Ho and Kaur note that the threshold in Singapore is effectively a significant harm threshold and the courts have consistently reflected in their judgments the view that judicial intervention "should be an avenue of last resort".[53] That said, while the bar has been set high, Ho and Kaur comment that it is not generally seen as prohibitive or inaccessible.

Other jurisdictions, such as England and Wales, have a lower threshold, intervening wherever the child's 'welfare' is at issue or their 'best interests' are not being met (used interchangeably in the case law). Belgium, Spain, and Hong Kong amongst others also use 'best interests' as a threshold; and given the likelihood that the Scottish courts may follow the English example, a similar threshold is likely operate under Scots law.[54] This is particularly likely as the English dicta align fairly easily with 'welfare test', set out in section 11 (7) (a) of the Children (Scotland) Act 1995, which covers disputes regarding all aspects of 'parental responsibilities' and 'parental rights'.[55] In Australia and other jurisdictions, decision-making authority differs depending the *type* of treatment. Parents may make decisions on therapeutically indicated treatment, but following *Re Marion*, where non-therapeutic treatment is proposed for minors, parents have no authority to consent, and instead a court or tribunal must provide consent for the procedure to go ahead. Stewart notes that "the distinction between therapeutic and non-therapeutic treatments has proved to be extremely

[50] M Dobernig, 'Parental Rights in Mexican Law', in this book.
[51] Lombard and Bracken (n 14).
[52] Buechler (n 22).
[53] Ho and Kaur (n 19).
[54] A Brown, ''Parental Rights', 'Best Interests' and the Withdrawal of Life-Sustaining Medical Treatment of Children in Scotland: A Lack of Authority'; I Goold, C Auckland and J Herring, 'Medical-Decision Making on Behalf of Children in English and Welsh Law: A Child-Centred Best Interests Approach', both in this book.
[55] s.11 of the Children (Scotland) Act 1995 sets out the court's powers in relation to parental responsibilities and rights; in particular s.11 (2) provides that, '[t]he court may make such order…as it thinks fit'.

difficult to apply and has created enormous uncertainty" and suggests that this leave open the possibility and "even a reasonable parental decision can be overturned by the court if it believes that it would be in the best interests of the child to do so".[56]

While it is clear that different thresholds for intervention exist between jurisdictions, it is important to note that how such disputes proceed in practice is not just a question of when the courts *can* (legally) intervene in a dispute between parents and doctors, but also how likely the dispute is to come before the courts at all. As seen above, the social and cultural values of certain countries may lead to the court rarely intervening in such disputes, even if they have the legal authority to do so, because of, for example greater deference on the part of doctors to parents, or on the part of the parents to the medical profession. Even if the court does become involved, as the following section demonstrates, there may be substantial variation in the ways in which the courts of different countries manage disputes, even where on the face of it, the legal standards to apply are the same.

## C. How Does Best Interests Operate?

While the authority (legal or de facto) for making decisions for children differs across cultures, many of those considered in this collection are guided in some form by the principle of deciding in the best interests of the child. This raises a series of questions for all jurisdictions, including who is best able to determine a child's best interests; what weight should be given to parental wishes when making this assessment, and how should value-difference and cultural variance be accommodated within the best interests assessment? It is clear from this collection, that different countries have answered these questions differently, with the result that despite seeming convergence in the law, there is substantial variation in the way that this is being applied in practice by the courts in different jurisdictions. While it is not possible to do justice to all of the ways in which differences emerged, in the final section, we hope to draw out some of the ways in which countries have varied in their approach to best interest decision-making, many of which have been touched on in the proceeding sections. Cultural and religious factors understandably shape differences in approach to decision-making on behalf of children, and one way in which this emerged was

[56] Stewart (n 48).

through differing attitudes to the weight given to the sanctity of life in best interest assessments,  A number of contributors drew out the strong commitment to the sanctity of life, and explained how this influenced the position of all parties. Israel and Greece were two such examples, while Ho and Kaur comment that as Islam is the recognized religion of Malaysia

> and the legal system is often referred to as being a hybrid system, being made up of both secular and syariah laws … It would thus appear that in matters which touch on issues relating to religious sensitivities (Islam in particular), the civil courts are unlikely to challenge any position taken by the religious authorities.[57]

It would therefore seem likely, they conclude, "that conservative religious positions such as sanctity of life arguments would be afforded great weight by the courts".

But a commitment to preserving life goes well beyond religious perspectives, with most jurisdictions evidencing a general preference to life-sustaining treatment where it was in the best interests of the child. Nonethelesswe can discern some differences in the ways in which jurisdictions have approached this aspect of decision-making. In South Africa, the right to life has been referred to as 'inviolable', with the court in one case ordering that transfusions be given to save a baby's life, despite the parents' religious beliefs that led them to refuse the treatment. In most jurisdictions, the right to life (or at least the child's interest in continuing to live)is, however, weighed against other factors. This often operates as a rebuttable presumption in favour of the sanctity of life. For example in Canada, MacIntosh notes that

> the presumption that pursuing life-sustaining treatment is in the best interests of a child has been rebutted in several Canadian decisions where the prognosis had uncertainties, and there were significant concerns about quality of life and/or challenges post-surgery or treatment.[58]

Courts now take the view that life without awareness may not be in the child's best interests, and so judges have begun to support the withdrawal of medical treatment without benefit (and where it may, in fact, be harming such as causing pain) where there is no chance that the child will regain awareness, despite the objections of parents.[59] English law takes a somewhat similar approach. While in both *Gard* and *Evans,* the court supported applications by hospitals to withdraw life-sustaining treatment against the wishes of the parents, asthe recent *Raqeeb* decision suggests, where the child is unlikely to suffer harm, life-sustaining treatment may be permitted to continue if the parents wish it too even though the treating medical team

[57] Ho and Kaur (n 19).
[58] MacIntosh (n 45).
[59] ibid.

does not consider it in the child's best interests.[60] In fact one interesting dimension to this case was that the parents wished to have Tafida moved to Italy precisely because it was felt that the Italian courts attached greater weight to the inherent good of continuance of life when assessing best interests, with the result that life-sustaining treatment would not be withdrawn from her unless she suffered brain stem death, demonstrating the differences in the way the best interests standard is applied across jurisdictions.

By contrast with Canada and England, in Israel, where the commitment to sanctity of life holds particular sway, courts will override the wishes of parents who wish for life-sustaining treatment to be stopped because

> sanctity of life (or the legal right to life) is given preference over prevention of pain and suffering. … Israeli law … promotes sanctity of life as the dominant consideration, particularly when the child is not terminally ill but suffers from an incurable condition. This violates the right of a child to avoid a life full of pain and suffering when the proposed treatment is futile and prolongs life artificially. Only when the child is terminal does the law provide a mechanism to respect requests by the parents to withhold treatment though there is no obligation on the courts or institutional ethics committees to accept these requests.[61]

Pain and suffering will not therefore necessarily override sanctity of life considerations. Malaysia, Peru and Argentina also evince a strong commitment to sanctity of life, in part due to religious influences prevalent in those jurisdictions.

One particular issue that has emerged is what ought to happen where parental views conflict with the doctor's assessment of their best interests. In these circumstances, the weight given to parents views varies. In some countries the deference to parents is so great that parental views are likely to take precedence notwithstanding the best interests standard. In China for example, Chunyan notes that;

> the best interests of the child principle laid down in article 35(1) of the GPCL has hardly restricted how guardians make proxy medical decisions for children. Hospitals and medical practitioners always follow the guardian's proxy medical decision even though it appears prejudicial to the child where the guardian refuses a treatment proposed by the treating doctor.[62]

There are also judicial statements in a number of jurisdictions that evidence the courts' commitment to respecting parental choice insofar as is possible. For example, in Australia in *Director Clinical Services, Child & Adolescent Services v Kiszko,*[63] O'Brien J reiterated the

[60] *Raqeeb v Barts NHS Foundation Trust & Anors* [2019] EWHC 2531 (Admin).
[61] Gilbar (n 30).
[62] Chunyan (n 9).
[63] [2016] FCWA 75.

assertion made by Thackray CJ in an earlier decision that the court 'should not interfere in the exercise of parental responsibility unless there is some clear justification for doing so.'[64] Parental discretion is given similar levels of respect in the United States by the courts; as Leslie Francis et al point out, "the state generally respects parental decisions except when they place a child's health, well-being, or life in jeopardy".

In Switzerland, meanwhile, the best interest of the child "must be based on objective criteria", with " the starting point for the assessment of the child's welfare [being] the medical indication". Parental religious views "may not endanger the welfare of the child", with the prime example of parental refusals of blood transfusions for religious reasons being considered contrary to the objective welfare of the child.[65] Mexico takes a similar position, holding that parental rights "do not confer authority over the life and death of their children. Parents would then have no right to affect the health of their children by virtue of their beliefs or customs".[66]

In the preponderance of English cases, the medical view has been supported by the courts, but as Jo Bridgman's work demonstrates, this may be because it is only those cases in which the parents' views are very likely to harm the child (or, as she puts it, cannot be followed by the doctors as they conflict with their conscience).[67] For example, while the parents' Muslim beliefs were upheld in *Raqeeb*, much of the judgment focussed on the lack of harm to Tafida, who would not experience pain or have any awareness of her situation. This can be contrasted with *Gard*[68] and *Evans*,[69] which both involved children who may have been able to experience pain and discomfort, which was crucial in the court's determining that, contrary to their parents' wishes, it was not in their best interests to be kept alive.

This raises a final point, that while many jurisdictions do apply a best interests standard, this may not reflect the reality of how these disputes are governed in practice. In England, as noted above, the touchstone for the court overriding the parent's decision may in practice be

[64] ibid [72]. Stewart chapter
[65] Buechler (n 22).
[66] Dobernig (n 50).
[67] J Bridgeman, 'Parental Responsibility, Professional Conscience and the Protection of the Court?' in I Goold, J Herring and C Auckland (eds), *Parental Rights, Best Interests and Significant Harms: Medical Decision-Making on Behalf of Children Post-Great Ormond Street Hospital v Yates* (Hart Publishing, 2019).
[68] n**Error! Bookmark not defined.**.
[69] n**Error! Bookmark not defined.**.

closer to a risk of harm threshold. Francis et al suggest the approach in the United States, in some states at least, is similar,[70] while Cameron Stewart suggests that the Australian approach proposed by Thakeray CJ "is very close in flavour to the principle of 'risk of significant harm'", suggesting a "primacy for parental decision-making and a preference for the court not exercising power in cases when the parental decision is clearly not incorrect or badly made."[71] In China, the threshold for interfering with parental decisions is even higher. When evaluating the approach of different countries to managing disputes therefore, the legal position is only part of the story. While the concept of the child's best interests has proven to be important across many of the jurisdictions, this collection reveals substantial variation in the way that the courts have applied a 'best interests' test in practice, with decision-making ranging from utilitarian and centred on the well-being of the family, to highly child-focused.

## D. Cultural Competence

One final theme that comes out in a number of chapters in this collection is the need for cultural competence, and sensitivity to the beliefs, practices and interests of minorities and indigenous peoples; which represents a challenge for courts applying a 'best interests' standard. MacIntosh's chapter traces some of the deeply problematic treatment of Indigenous people in the Canadian context, and Ben Gray urges us to understand "the value of abandoning the idea of a common morality and objective best interests".[72] So much of what we see in the way jurisdictions have approached decision-making for children rests on trying to determine the one, best way for that child – what is, purported, in their 'best interests', or what best promotes their welfare (or that of a wider family). But as Ros McDougall's chapter demonstrates, such an understanding of welfare is flawed.[73] It is this very notion, that there is one best approach, that has led to a failure to be sensitive to cultural differences. It is also to some degree the foundation stone of conflict, not all conflict, but some. Gray argues that accepting that there are no objective best interests shows us that "the way forward will be found through compromise of both parties, rather than further analysis to find the best interest". We should, he argues, be developing approaches that facilitate trust and

[70] Francis et al. (n 46).
[71] Stewart (n 48).
[72] B Gray, 'The Relevance of Cultural Competence to Resolving Disputes in Relation to Medical Decisions for Children', in this book.
[73] R McDougall, 'Identifying Who and What, Then How: Attending to the Role of the Decision-Maker in the Normative Debate About the Best Interests Standard', in this book.

communication, and support relationships in which these can be fostered. How each jurisdiction achieves that will differ, but we hope that the chapters in this collection offer some insights into ways forward.

## E. Conclusion

What can we take from this comparative analysis? Should we, in fact, take any lessons from it at all? In our view, looking across jurisdictions, contextualised by their social and cultural differences, we can all gain from learning about the strengths of other jurisdictions' approaches. Some are less combative, and arguably this might be a good thing. Others are more adversarial, but then having open, clear debate about where decision-making authority lies may also be a valuable approach. Perhaps the most important thing to take from this analysis, however, is the need for cultural sensitivity; recognising that there will be differences within communities, and that these need to be respected and accommodated in the way our legal systems deal with decision-making on behalf of children. We might think that there should be few lessons to draw from a comparative analysis precisely because our differences mean that different approaches suit different contexts and cultures, and we should not then seek to transpose the approach developed for one jurisdiction on to another. However the very conclusion that there is more than one way to think about what is best for a child, and that we do not all share the same values, is in itself important. Once we accept this, we should then see that we need to make space for differences of view and allow for this within the way decisions are made. This does not need to mean allowing any decision, but it does mean approaching disputes with an open-mind and a willingness to engage with those differences and work towards creating a system that can accommodate value disagreements while still protecting these most vulnerable members of our community. Arguably, an approach that aims to bring different perspectives together—courts, doctors, parents, and wider family—in a way that all are heard, in a manner aimed at informed and culturally sensitive consensus-building should be the goal in this area of law in any jurisdiction.