ETHICAL CARE OF THE CRITICALLY ILL CHILD: A CONCEPTION OF A ‘THICK’ BIOETHICS

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In this article I argue for an interpretive approach to bioethics with critically ill children. I begin by highlighting the dominant Anglo-American bioethical framework that defines standards for ethical care in critically ill children and then outline a critique of this framework. Drawing predominantly on the ideas of Charles Taylor, Michael Walzer and Richard Zaner, I call for a reconception of bioethics and propose an interpretive ‘thick’ framework that is centred on culture and context. Finally, I illustrate this interpretive approach through a comparative study of two cases in pediatric intensive care: the narratives of Marc and Larry. These case studies reveal that ethical dilemmas in pediatric critical care can be traced to relational tensions over respect, trust and power rooted in the disparity of moral horizons among the persons involved.

Introduction

Great advances have been achieved in bioethics towards the promotion of ethically sensitive care. However, the reconciliation of the ethical dilemmas surrounding decision making with children has posed particular challenges. It is difficult to determine how to care for children when the numerous adult voices speaking on their behalf do not agree with each other.

My aim in this article is to outline some of the major limitations in applying the prevailing bioethical paradigm of principlism to children. This critique is followed by a call for an interpretive framework for bioethics. This framework implies a ‘thick’ bioethical analysis of the cultural context within which ethical dilemmas emerge. I will defend this call for interpretivism through an analysis of the philosophical foundations of moral problems in this context. This framework will set the stage for the process through which ethical dilemmas can be effectively reconciled – a mediational process that will be characterized as rapprochement.

This discussion is pertinent for nursing because it can foster a reflection on how the discipline ought to construe bioethical dilemmas in this setting. However,
this article is also directed more broadly to the health professions generally because the ‘thick’ conception of bioethics described here is implied as a transdisciplinary model. That is, the practice of ‘thick bioethics’ is not exclusive to any single discipline.

I will briefly introduce the cases of Marc and Larry, through which some of my argumentation will later be illustrated. Portions of these narratives that are not fundamentally relevant to the central concerns of this article have been modified in order to preserve the anonymity of the persons involved. The article conforms to the ethical standards commonly required for case reports.1

Marc’s story
Marc is a 10-year-old boy who presented to the pediatric intensive care unit (PICU) with respiratory distress. He had been diagnosed with mitochondrial myopathy five years previously, which resulted in progressive deterioration of his neurological status. A CT scan revealed that his brain is severely degenerated; he exhibits no voluntary function; he is stiff and frequently has episodes of motor spasms with significant grimacing. His current respiratory distress has been attributed to his respiratory muscle weakness coupled with a bacterial pneumonia. During a seven-day course of appropriate antibiotic therapy, his breathing continued to deteriorate to a point where he required a respirator in order to sustain ventilation.

Currently, the bacterial infection has been overcome and he has now been on the respirator for two weeks. The PICU physicians have concluded that the pneumonia was caused by an irreversible deficiency of his respiratory function; they predict that he will never be able to breathe on his own again. His current ventilator dependence superimposed on the frequent spasms and grimacing have led the medical staff to recommend a cessation of treatment, that is, to let Marc die. Most members of the PICU medical staff have stated that it feels inhumane to continue to subject Marc to such futile suffering. They believe that continued treatment is futile because it is highly unlikely that Marc will achieve any significant recovery.

However, his parents, who have been very devoted to and involved with Marc’s care, have opposed any withdrawal of therapy and want him fully treated. They have indicated that they reject that his condition is irreversible on at least two grounds. First, they believe that the physicians may be mistaken in the futile outlook that they have drawn for him. Secondly, this family is highly religious (they are Canadian-Italian Catholics). The parents have stated several times that they believe in miracles, and they are waiting for their miracle.

Larry’s story
Larry is an eight-and-a-half-year-old boy with spina bifida and an Arnold–Chiari malformation. He was admitted to the PICU two months ago for treatment of respiratory failure resulting from brainstem compression (by the Arnold–Chiari malformation). He is otherwise fully conscious and mentally alert.

In light of a number of neurosurgical procedures that he has already undergone, the physicians have judged Larry’s respiratory failure as end stage (that is, irreversible).
The parents have been informed that he will require permanent mechanical ventilation.

Larry’s parents have been very devoted to him throughout his life and have helped him to adapt to his various disabilities. They are concerned about his current and future quality of life because of his diminishing autonomy resulting from continuous dependence on a respirator. They have requested that mechanical ventilation be discontinued, to allow Larry to die peacefully and to avoid future suffering. Although some of the biomedical staff are ambivalent about this request, most are prepared nevertheless to respect the parents’ wish. However, two PICU physicians have currently expressed strong opposition toward the withdrawal of Larry’s life support, arguing that his suffering is not excessive and that he has the capabilities of enjoying a significant portion of his life.

Guidelines on life-sustaining treatment

The American Academy of Pediatrics Committee on Bioethics has published guidelines on consent and decision making with children. These state that, for children who cannot give consent themselves, parents should be responsible for granting permission for treatment while giving great weight to the clearly expressed views of the child. Situations involving older children and adolescents should also include the child’s assent, to the greatest extent possible. Decisions regarding life support for younger children typically call for the use of the ‘best interests’ standard, weighing the benefits and burdens of the various treatment options. The Canadian Pediatric Society has published similar guidelines. It is noteworthy that some prominent guidelines on ethical conduct for nurses do not provide any explicit statements regarding the care of children.

The recommendations of the American Academy of Pediatrics are consistent with the prevailing bioethical paradigm regarding the care of children. These are useful in that they help to establish the assignment of responsibilities for such decisions, as well as the decisional standards that ought to be applied. These recommendations give great weight to the clearly expressed views of the child. This has been partly justified on the basis of empirical research revealing the sophistication of understanding and decisional aptitude of which children can be capable.

However, the best interests standard and its reliance on surrogate decision making gives rise to some problems: (1) empirical studies of surrogate decision making (with adult patients) have reported high rates of disagreement with the treatment options that patients would have preferred; (2) in the context of children, it is difficult to determine which benefits and burdens are most significant; (3) it is problematic for a parent to distinguish the child’s interests from the parent’s own interests; and (4) questions can be raised about whether the interests of others (e.g. well siblings) are necessarily secondary to those of the patient. Surrogate decision making regarding a child’s best interests seems pragmatically troublesome. It is also morally limited because it subordinates numerous morally significant issues, such as those of other family members or health professionals.

In addition to these specific problems, the broader frameworks employed within Anglo-American bioethics have also been criticized. These critiques have charged...
bioethics with: (1) an excessive reliance on principles;\textsuperscript{10-13} (2) a covert prevalence of legalism;\textsuperscript{14} and (3) an inadequate social attunement.\textsuperscript{15-17}

Examining the philosophical foundations of moral discourse

The prevalent framework in Anglo-American bioethics is referred to as principlism. Principlism appeals to some dominant ideas within western philosophy that favor universal moral frameworks.\textsuperscript{18} However, universalism has been critiqued within moral philosophy. These critiques argue that morality is deeply rooted in culture and context, and thus frameworks that aim to ‘isolate’ universal moral principles are fundamentally flawed. For example, Stuart Hampshire has called for a recognition of practices within the local customs of a community.\textsuperscript{19} In Charles Taylor’s view, morality is shaped by culture, that is, within cultural frameworks of significance. In his philosophical analysis of western modernity, Taylor has put forth a sustained argument for a cultural (rather than an acultural) conception of moral agency.\textsuperscript{20-22}

Taylor construes a moral framework as a ‘horizon of significance’ from which a person’s life derives its identity, shape and meaning. This relates to the constellation of valuations that form one’s moral community. These valuations consist of the goods and ends of life that represent the standards by which our desires and choices are judged. A moral framework provides the background of our moral life for what matters. Taylor roots our horizon of significance within culture. Human life takes shape and meaning from the ‘webs of significance’ that are woven by a culture.

Anthropologist Clifford Geertz\textsuperscript{23} has further characterized culture as a system of significances. Culture shapes the knowledge and practices of a particular community, and how things matter for people within that community.

This culturally-centred conception of morality should be examined and understood through ethnography. This is a qualitative method based on participant observation, wherein the ethnographer is immersed in the context under enquiry. Ethnography is a kind of intellectual effort venturing in ‘thick description’ of such a system of significances. I recognize that alternative conceptions of ethnography have been articulated within anthropology. Geertz’s views are not universally held within that discipline. I have chosen to highlight Geertz’s ideas because: (1) his work is highly acclaimed within anthropology as well as in other disciplines; and (2) his ideas have been directly related to moral discourse within both anthropology and moral philosophy.

Ethnography has been embraced by some bioethicists because it can trace the relativist (rather than universalist) cultural systems of meanings that shape the lives of persons within a community.\textsuperscript{24} In a particularly relativist example, Michelle Rosaldo examined headhunting among young male Ilongot natives (in the Phillipines), which she described as a practice that releases youthful energy and perpetuates authoritative relations between male youths and male elders.\textsuperscript{25} Although she expressed her own discomfort with the brutality of headhunting, the Ilongot are represented as suffering no moral tension over this killing. For Rosaldo, the moral significance of headhunting is locally constructed by the community.
Striving to reconcile the universalist-relativist polemic

This universalist-relativist polemic on morality and culture highlights a fundamental tension in moral discourse. Whereas we may recognize that morality is a highly relativistic phenomenon, moral discourse often involves conflicts arising out of divergent (moral) viewpoints, between members of different cultural communities, for example. This gives rise to a striving for some general (universal) notions on morality that enable a comparative examination of moral problems across contexts and viewpoints. Moral analysis and decision making require a conception of moral discourse that reconciles the tension between these relativist versus universalist positions.

‘Thick and thin’ moral discourse

Political philosopher Michael Walzer has attempted to reconcile the polemics of relativism and universalism in moral discourse through his ‘thick and thin’ framework. Although his work focuses on moral argument within political philosophy, I believe his ideas shed some light on how to reconcile this problem in bioethics.

Walzer argues against the philosophical practice of isolating a set of universal moral principles that can be related across cultures and historical periods. He strives to offer a thick description of morality, a viewpoint he defines as ‘richly referential, culturally resonant, locked into a locally established symbolic system of network of meanings’ (p. xi). For Walzer, moral analysis is necessarily maximalist, or thick. Morality is always thickly bound to a cultural context. However, as we look at cultural communities, we can discover some moral norms that are held across cultures. These moral norms are minimalist or thin whenever they are disengaged from the particular contexts from which they emerged. They are animated with meaning within local cultural life. Such minimalist norms can include negative injunctions against murder, deceit, torture, oppression and tyranny.

Walzer’s framework roots moral discourse deeply within local culture yet recognizes the potential for minimalist spheres of convergence across cultural frameworks. However, Walzer does not elaborate a process for cross-cultural discourse. How can distinct communities talk to each other to sort out their commonalities and disparities? Consequently, I have turned to Charles Taylor’s notion of a ‘politics of recognition’ within the multiculturalist context to help to fill this void.

Taylor relates multicultural tensions to the human need for recognition. He argues against a ‘politics of difference’, which aims to make judgements of equal worth across cultures. He criticizes these as an attempt to endorse, homogenize and praise the other for ‘being like me’. Instead, Taylor proposes a politics of recognition based on the premise that cultures that have provided the horizon of meaning for large numbers of human beings... over a long period of time... are almost certain to have something that deserves our admiration and respect... What it requires above all is an admission that we are very far away from that ultimate horizon from which the relative worth of different cultures might be evident (pp. 72–73).
A politics of recognition involves a transformation of standards and developing a new vocabulary of what constitutes worth that we could not possibly have had at the beginning, a process that Taylor adapts from Gadamer called the ‘fusion of horizons’. This formulation rejects efforts to try to come up with which culture is ‘right’ or ‘most right’ on a given issue. A politics of recognition sets out a work of reciprocal understanding – a rapprochement – upon which to cultivate a cross-cultural framework.

Seeking a thicker bioethics

A recognition of the fundamental significance of culture and context in morality requires a shift in the practice of bioethics. I would like to propose a maximalist ‘thick’ bioethics. Bioethical discourse will need to consider sociocultural analyses reported in ethnographic accounts of medical problems. For example, anthropologist Margaret Lock’s thick comparative study of organ transplantation and brain death in Japan and North America traces the emergence of brain death criteria, and the implicit redefinition of death, to covert pursuits and interests within the transplantation industry that are asserted publicly in terms of the social interests of prospective recipients and neurologically impaired donors.28

In addition to drawing upon ethnographic accounts for their content, the practice of bioethics should seek inspiration from the method of ethnography. The ethnographic skills of cultural translation and analysis should become necessary proficiencies for the practice of bioethics. For example, in their study of informed consent among Native Canadians, Joseph Kaufert and John O’Neil have illustrated how ethnographic methods can thicken our understanding of problems within bioethical discourse.29 They described how medical clinicians and Native patients conceived illness and healing in very different ways. Their relationships were characterized by significant power and control imbalances.

What counts as culture?

In my call for a culturally thick conception of bioethics, I understand culture as a system of significances and practices elaborated by a particular community over time. Culture emerges as a horizon against which individual experiences have particular meaning. Culture functions as a pervasive explanatory framework that shapes the way persons understand specific situations, as well as the significance of their lives in general.

Thus, culture is not limited to ethnicity or religion. Cultural identity can relate to multiple forms of community, such as membership of social class, gender or professional groups. Each person involved in a clinical encounter is simultaneously affiliated with a multiplicity of cultural communities. These converge in a particular way for that particular person, shaping his or her particular moral outlook. Such outlooks can be traced, through thick description, to moral horizons shaped by the convergence of that person’s community affiliations. In light of the complex multiplicity of sources that contribute to a person’s moral outlook, understanding a person’s views requires an ethnographic process of thick description.
A thick conception of bioethical practice

A thick bioethics will need to be centred on the cultural context of clinical situations. A number of bioethics scholars have already formulated several contextualist frameworks for the practice of bioethics. Among these, interpretivism is premised on a conception of human agency wherein moral life is rooted in a sociocultural context, seeking to understand human experience through thick contextual description. Interpretivism is premised on the notion that understanding in human experience inescapably involves interpretation. I interpret an encounter in terms of my acquired understandings (shaped through culturally and temporally embedded prior experiences). In turn, my experience of a particular encounter will reshape my interpretive framework, that is, my system of understandings that I bring to subsequent encounters.

Among the proponents of interpretivism in bioethics, Richard Zaner has published the most elaborated and sustained articulation. He has outlined a framework that is centred on the experiences of participants within the clinical encounter. Zaner argues that experience is the point of departure and return for theory … [However] encounters are also socially framed by prevailing values, written and unwritten professional codes, governmental regulations, hospital policies, unit or departmental protocols (pp. 230–31).

Zaner describes his method in bioethics as a process that starts with a putting aside of all prior convictions, reflective attention to the inherent intentions of particular actions, and judging on the basis of sound experientially relevant evidence. Whereas an ethnographer aims to articulate a thick description of social life (including moral agency), an interpretive bioethicist within the clinical setting is required to go further. The bioethicist is also required to enable a resolution of the conflict. An interpretivist enables this resolution not by serving as a moral judge or expert on what should be done but by facilitating a complex conversational process among decision makers; that is, within their own respective moral frameworks, with the aim of reaching decisions that are as consonant as possible with each participant’s own respective moral framework within the given circumstances.

This construal of bioethics is compatible with Taylor’s process of cross-cultural recognition – or rapprochement – that aims to ‘fuse’ conflicting moral horizons. This reorients the aims of the bioethicist away from a role of expert arbiter towards that of a mediational agent. Within this mediating role (aiming to bridge disparate moral views) the bioethicist also guides this process in a manner that recognizes prevailing social and professional values and obligations, as well as relevant laws.

Narratives of suffering, obligation and care – the thick lives of Marc and Larry

Detailed notes on observations, conversations and contextual particulars were recorded for the cases of Marc and Larry, producing 50–70 pages of text for each one. A synthesis of these was produced in the form of 15-page narratives for each one. I will succinctly outline interpretive analyses of these narratives below.
Horizons of moral significance

The stories of Marc and Larry are unique, each bearing a number of fundamental distinctions. On the other hand, these two very different narratives converge in a number of remarkable ways to highlight significant similarities.

Although both boys were afflicted with severe disabilities, Marc’s predicament was particularly distinctive in terms of his extensive mental impairment. This impairment raised concerns among the biomedical staff about his capacity to enjoy life. Indeed, they believed he was constantly suffering. Marc’s parents (Maria and John) interpreted his emotional and mental experiences very differently, much more ‘positively’. Whereas the parents attributed these differences of view to the intimacy of their relationship with Marc, the staff attributed the differences to the parents’ psychological denial of reality – their inability to accept Marc’s reality.

This difference in views between the parents and the staff unfolded as a conflictual disagreement whereby each ‘side’ claimed to have a greater authoritative claim over ‘knowing’ Marc’s experience. The parents rooted the legitimacy of their claim in their intimacy with Marc, while the staff supported their claims within their professional experience with children like Marc and the corresponding psychological responses of parents like Maria and John.

The disagreement was intensified by a number of underlying premises that were not openly recognized. The parents suspected that Marc’s affliction was caused by a medication error (a suspicion for which no evidence could be traced). Additional tension emerged in relation to a wide margin of imprecision in the prognostication of Marc’s overall condition, such as early predictions that he would not return home that were subsequently disproved. This provided the parents with justification for questioning other aspects of Marc’s prognosis.

In short, the staff interpreted events from their biomedical framework while Marc’s parents interpreted contradictions and uncertainties from their framework of suspicion and distrust. These disparate viewpoints seemed to foster an increasingly growing distance between the staff and the parents. For example, Marc’s parents had deeply held religious views and believed that humans should not voluntarily permit the ending of life. Human life in any form held a special sanctity. They held their religious views above their biomedical views and therefore believed that God could transcend biomedical explanations and predictions at any time. They wanted to wait and hope for their miracle. Meanwhile, the biomedical paradigm tends to regard religion as a culture’s particular ‘beliefs and rituals’, a form of understanding subordinate to science. Here again, authoritative truth claims emerge competitively, with little common ground for reconciliation. Their respective views were mutually rejecting.

Furthermore, both Maria and John came from cultures in which it was considered wrong to abandon sick family members. These parents were not speaking in terms of a ‘right’ to decide for Marc or a ‘right’ to sustain his life. Rather, these parents spoke in a language of duty and obligation. Within their tradition, it was their duty to sustain and care for their loved one. These traditions were inescapably binding.

For Maria and John, these duties were ‘close to the bone’ and unquestionable. They were shaped by and expressive of their membership of a broader cultural way of life – of being Italian – from which they derived their deeper sense of identity and meaning. On the other hand, the clinical staff approached Marc and his parents from a professional ethical tradition that required them to attend to Marc’s best interests,
construed as the balance of benefits and burdens related to medical care. In light of their disparate views on Marc’s experience, it seemed inevitable that they would disagree in their judgement of Marc’s current interests. Each side appealed to reputable traditions in their authority claims over what was best for Marc, with scarce common ground for reconciliation.

In contrast, Larry’s case involved Tom and Laura (his parents) and their wishes to discontinue life support. Tom held a consistent view towards the cessation of life support, while Laura’s views fluctuated throughout the course of the case. It was remarkable that, during the period of intense discussion with specialists, a strong agreement emerged among professional staff and both parents to end life support. This raises a question about the potential for ethical dilemmas in the absence of overt conflict: Does the absence of disagreements signify the absence of ethical problems? This was apparently not the case. When two partially involved physicians opposed the plan to withdraw life support from Larry in order to prevent future suffering, this opposition seemed to facilitate the explicit expression of ambivalence by other staff (particularly Larry’s primary physician) and what appeared to be a covert ambivalence within the mother. Until this case was confronted with opposition, the prevailing staff views as well as the mother’s were in favor of the dominant parent’s wishes.

The various agents held numerous common understandings. There were no disagreements over Larry’s diagnosis and the parents accepted medical predictions of his outlook. A further realm of common views was the central criterion employed for life-support decisions. Both parents and staff valued life but only insofar as it was not disproportionately burdensome. There was no appeal to a ‘higher good’ beyond the individual potentialities of Larry’s life.

The disagreement that ultimately emerged involved a dispute over how much disability was too much. Tom and all of the specialists consulted in this case regarded a permanent dependence on a respirator as excessively and cumulatively burdensome. Opposing staff (and possibly the mother) attributed special significance to the fact that Larry was mentally ‘normal’ and capable of a number of enjoyments. For example, he enthusiastically enjoyed loud heavy metal music. There was some questioning of whether (and how) Larry should have an explicit ‘say’ in decisions regarding his care.

A disparity of moral horizons

This comparative study of the cases of Marc and Larry reveals that a discussion of the merits of a particular life is inescapably rooted in the discussants’ broader moral outlooks. The central tension is not about who has the highest order right to decide for a child but about the expression of numerous moral obligations rooted in a multitude of moral horizons. These horizons will converge and diverge across the many spheres of moral life, resulting in various forms of agreement and disagreement about what should be done. Moral conflict typically involves a clash of horizons, the confrontation of disparate viewpoints.

The parents of Marc and Larry differed in their views on the aims of life and familial responsibility. These differences were traced to distinctions in their respective cultural viewpoints. However, in spite of the significance of culture in shaping moral frameworks, remarkable distinctions emerged among agents with similar cultural horizons (for example, between Tom and Laura, or among various professionals working within a shared biomedical paradigm). Although culture is
fundamentally formative of moral horizons, moral viewpoints are further elaborated in a cultural community within the realms of its agents’ particular histories and context. It is important to guard against an essentialism of culture, wherein we presume the moral views of persons on the basis of their membership of one particular community.

Rather, it seems plausible that additional spheres of human life are also determinative of moral views. Culture can converge with a number of other potentially relevant spheres of human life (such as age, gender, personal history or social circumstance) in shaping the moral outlooks of particular persons at particular times. The cases of Marc and Larry have also illustrated that moral dilemmas can emerge overtly (and expressed through disagreements) or covertly (nestled within the ambivalences of silent agreements).

**A relational enactment of moral life**

This contextual study has also illustrated that moral discourse in the clinical encounter is enmeshed within complex relational phenomena. Regardless of the sources of disparate views that emerged within the cases, these disparities were expressed through struggles for respect, trust, and power.

**Struggling for respect**

Within each disparity, agents sought to have their own views respected. These disparities typically involved insufficient commonalities that could enable a genuinely respectful acceptance of the other. Disagreeing agents lacked an adequate common ground upon which disagreements could be resolved.

This resembles what Taylor has described as the search for mutual recognition among interdependent communities. This striving for an equal recognition of differences is doomed to fail (according to Taylor) because each agent judges worth in terms of his or her particular moral outlook. These outlooks can be highly divergent and incommensurate. Thus, the pursuit of equal recognition cannot in many instances express genuine respect.

The case narratives suggest that this striving is comparably apparent within the relationships of the clinical encounter. Patients, families and clinicians confront an inescapable interdependence within the context of disparate moral frameworks. These encounters gave rise to ambivalences and disagreements that could be traced to broader disparities. These persons struggled to agree on courses of action, while they held significantly different views, striving (and expecting) to have their own particular views respected.

**Struggling to trust**

Disparities also gave rise to ‘clashes of intentions’ whereby conflicting agents assigned motivational aims to the other from their own respective understandings. This contributed to a climate of prejudgement where one person’s actions were (mis)interpreted from the disparate viewpoint of the other, resulting in an escalating cascade of silence and distrust.
The clinical encounter involves an obligatory trust relationship that is not subject to the limits, conditions and checks for trust that are possible in ‘ordinary’ relationships. Patients and parents are required to confide and rely on strangers for matters that involve deep vulnerabilities in a manner that circumvents the ways in which people form genuine trust. They are thrust into a position of obligatory trust.

**Struggling for power**

Finally, severe illness gives rise to profound vulnerabilities and dependencies on others. Parents are particularly disempowered by the asymmetry inherent in their relationship with the staff in terms of specialized knowledge, skills, control over critical resources, and the power resulting from these. Thus, parent–staff relationships inherently involve a power dimension. This was particularly apparent in the narratives when agents engaged in competitive truth claims over who had the most authoritative understanding of what was best for the child. The disparities in moral views contributed further to these power conflicts.

**Summary**

In summary, the principal finding of this interpretive analysis is that the clinical encounter in pediatric critical care can give rise to relational tensions (over respect, trust and power) rooted in the disparity of moral horizons among the persons involved.

**Implications for bioethical practice**

I will conclude with a brief outline of what this discussion implies for bioethical practice and decision making. These contextual analyses suggest that moral dilemmas within the clinical encounter involve conflicts between disparate moral viewpoints. These are best understood through an ethnographic method of thick description. Also, the narratives of Marc and Larry demonstrated that moral discourse involves a relational enactment; the negotiation of moral views is transacted within the ‘politics’ of relationships. The relational phenomena of respect, trust and power emerged as social tensions resulting from, and constitutive of, moral conflict.

I have also argued that the practice of bioethics consists of more than just describing and interpreting cases thickly. Rather, it involves a further effort towards the resolution of ethical dilemmas. Within the moral framework of this article, I have described this as an essentially mediational work, a process of rapprochement. The bioethicist seeks to reconcile conflicts among the multiple voices in the clinical encounter by seeking to ‘fuse’ the disparate moral views.

This should draw on a mediational process, beginning with an identification of some common ground and common language. For example, the conflicting agents could come to agree that they all (1) want what is best for the child, (2) wish to comfort the child’s suffering, and (3) then seek to elaborate what each means by ‘best’ and ‘suffering’, and so on.

The clinical encounter can be enriched through the engagement of a bioethicist practicing from a thick interpretivist framework. A thick bioethics requires immersion

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in the particulars of a case. The bioethicist would attend the various team meetings, but also seek engagement with patients and families in pursuit of ‘silent voices among the vulnerable’.

Although a thick bioethics is centred on context, this should not necessitate a slide towards extreme relativism. Rather, the bioethicist serves as a liaison with the broader (legal, medical and bioethical) norms that may be relevant to the case at hand. For example, although Larry’s parents and PICU caregivers may have reached an agreement to discontinue life support, a consulting bioethicist would have likely challenged this decision on the basis of the bioethical best interests doctrine outlined earlier. Given that most persons concerned with Larry indicated that his life involved some significant enjoyments (and, if asked, Larry would likely wish to continue living), it could be argued that the ending of life support would not serve his current best interests.

A bioethicist with a comprehensive knowledge of the relevant legal, professional and bioethical norms should seek to ensure that clinical practices conform with the recognized doctrine. This doctrine could serve as minimalist moral views that are necessary but not sufficient for ethical care. The bioethicist would aim to ensure that this minimalism is respected across cases, while seeking to ground the moral discourse of a specific case within the maximalist particularities of that local context.

I envisage a practice that resembles that of a mediator engaged in the resolution of a marital breakdown. The mediator recognizes that the separating adults can freely choose from a wide range of possible forms of independent life. Yet the mediator will intervene to ensure that some minimal conditions are respected regarding the interests of (vulnerable) children, within the thickly understood contexts of everyone involved.35–37

A thick bioethics involves a recognition that there is no consensus on the ultimate goods that the clinical encounter should pursue. The ethical care of critically ill children requires a rapprochement of the various moral voices speaking for the child: parents, physicians, nurses, other professionals, the state, and the children themselves. The bioethicist seeks to reconcile the disparate views of these agents, attentively listening to the many voices as well as to the actual utterances and expressions of the ill child, in a manner that is congruent with widely accepted (universal) views, while attuned to the contextual and relational dimensions of moral life.

I suspect that many bioethicists, in nursing as well as other disciplines, actually practice according to this thick mediational model, although this may not be formally acknowledged by the prevalent paradigm.

**Listening to Marc’s narrative: striving to reconcile the disparities**

Marc’s family, physicians and nurses had deep disagreements over what should be done. Confronted with their interdependence, they engaged in numerous conversations – painful exchanges of divergent viewpoints – each agent being unable to escape from hearing the views of the others. The parents were approached on three occasions to discuss a do-not-resuscitate order. They vehemently (and somewhat angrily) replied that Marc was their son whom they loved deeply and who they believed to be entitled
to all possible care to allow God an opportunity to offer a miracle. Meanwhile the caregivers persisted in revisiting the parents’ categorical demand for unrestricted life support as his condition continued to deteriorate. His skin was so poorly perfused that it started to break down. Numerous infections were developing. Many of the caregivers were haunted by feelings that they were torturing this child who suffered severe spasms and had a very limited prognosis.

These confrontations resulted in some negotiated agreements. For example, in response to the caregivers’ concern about Marc’s suffering, the parents agreed to his receiving deep sedation and analgesia, even though this could cause greater instability. Everyone agreed that comfort should hold a high priority.

This continued for a few days until one evening when his heart function diminished dramatically. The caregivers immediately prepared to perform cardiopulmonary resuscitation (CPR). The parents seemed to understand fully what was happening because they had heard about this so many times before. As they cried and sobbed, the mother threw herself on Marc’s chest and said out loud: ‘Stop, stop, stop.’ CPR was not performed as Marc’s parents painfully mourned their loss.

In the end, the parents were able to ensure that everything possible was done for their precious child, while the caregivers were not required to perform the CPR that they considered to be wrong.

References
