May the Real Surrogate Stand-Up: A Pluralist Critique of the Shared Decision-Making Model in Neonatal Intensive Care

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Abstract

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In the fast-paced environment of the neonatal intensive care unit (NICU), decisions about the health care of newborns involve multiple - and sometimes competing - normative forces. Informed by critical legal pluralism, this thesis offers an analysis of the normative interactions that emerge when parents and health care professionals meet at the bedside of a critically ill newborn. Using the shared decision-making model favored by the Canadian Paediatric Society (CPS) in its 2004 position statement on treatment decisions regarding infant, children and adolescents, I claim that in the NICU context consent is not sought in cases of medical certainty, where the best interest of the patient has already been ascertained according to medical norms. Consequently, the “shared” component of decision-making occurs only after the cause for decision-making has been determined by the child’s health care team and presented to the child’s surrogate decision-makers. Using ethnographic studies on the lived experience of parents in NICU, I question the marked difference between the authority given to parents by Canadian legal and medical guidelines and the authority they are allowed to exercise in fact at their child’s bedside. I conclude by a critical reflection on the emergence of plural law in the NICU trough dynamics of parental resistance or conformity to accepted medical norms.

Résumé

Que le véritable substitut se lève: Une critique pluraliste des décisions partagées aux soins intensifs de nouveau-nés

À l’unité des soins intensifs néonataux, les décisions portant sur le traitement des nouveau-nés impliquent une multitude d’influences normatives dont certaines peuvent entrer en compétition. Mettant à contribution le pluralisme juridique critique développé par Martha-Marie Kleinhans et Roderick Macdonald, cette thèse offre une analyse des interactions normatives qui émergent lorsque parents et personnel traitant se rencontrent au chevet d’un nouveau-né à l’état de santé précaire. En me basant sur le modèle de décision partagée favorisé par la Société Canadienne de Pédiatrie dans son énoncé de position sur les décisions médicales concernant les enfants et les adolescents, je soutiens qu’en contexte de soins intensifs néonataux, le consentement des parents n’est recherché qu’en cas d’incertitude ou de neutralité thérapeutique et non lorsque l’intérêt de l’enfant peut être adjugé avec certitude en vertu de critères médicaux. Par conséquent, la dimension « partagée » du processus décisionnel ne prend place que lorsque le personnel traitant estime qu’une incertitude suffisante justifie l’implication des parents dans le processus décisionnel. À l’aide d’études ethnographiques sur l’expérience vécue des parents à l’unité des soins intensifs néonataux, je souligne la différence marquée entre l’autorité décisionnelle donnée aux parents par le droit formel canadien, incluant les directives médicales, et l’autorité qu’ils exercent *de facto* au chevet de leur enfant. Je conclue par une réflexion critique sur l’émergence du pluralisme juridique aux soins intensifs néonataux par les dynamiques d’accommodement ou de résistance des parents envers les normes médicales en vigueur.

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The only persons who seem to have been left out of the list of acknowledgements … are Adam, Euripides, Genghis Khan, Alpha Centauri and my cats. – K.N. Llewellyn, *The Bramble Bush, on our law and its study* (New York: Oceana, 1951) at 8.

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Introduction

In the neonatal intensive care unit (NICU) treatment decisions are made quickly and often. Reacting to his perceived irrelevance in the care of his premature son a father declared:

> "The perfect parent of a premature baby that's in that intensive care nursery is that parent that comes up ten minutes on Sunday and calls once a day. That way you're not in their way. You just come get the baby when he's ready to go home. And…they give you a big slap on the back and say what a great job they've done."[1]

Legal scholarship on the role of parents in neonatal decision-making has been focused in many cases on the juridical aspects of the decision-making process. Canadian formal law on surrogate decision-making hinges on a procedural component (who should make decisions on behalf of incapable minors?) and a substantive component (on what basis?). However, formal rules and guidelines do not address the norms that inform the decision-making process. Bioethical research has deplored the inadequacy of formal legal rules to address adequately the circumstances of families facing difficult decisions in the care of a critically ill child.[2] In the critical care environment, where most treatment decisions[3] contain an element of ethical uncertainty, intimately personal normative influences such as beliefs, values, morality and conceptions of health, illness, life and death come to weigh heavily in the surrogate decision-making process. The monist view

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[1] Winnifred Ellenchild Pinch, *When the Bough Breaks: Parental Perceptions of Ethical Decision-Making in NICU,* (Lanham: University Press of America, 2002) at 78.

[2] See e.g. K.C. Glass & F.A. Carnevale, "Decisional Challenges for Children Requiring Assisted Ventilation at Home" (2006) 18 HEC Forum 207 at 208; see also F.A. Carnevale, "The Birth of Tragedy in Pediatrics: A Phronetic Conception of Bioethics" (2007) 14 (5) Nursing Ethics 571 at 573.

[3] In the context of this thesis, the term "treatment decisions" refers to medical decisions made jointly by parents and health care professionals. The term presupposes either a choice between different medical treatments or between treatment and non-treatment.

of law[4] as emanating from a single source is not adequate to explain the complexity of law-like interactions guiding medical decision-making at an infant's bedside. The process of making the *right* treatment decision within the confines of procedural and substantive formal norms challenges legal theory to identify normative influences that, while unrecognized by institutional law, exert a significant authority on the behavior of decision-makers.

This thesis proposes to study the normative underpinnings of decision-making in the NICU. It will examine how the shared decision-making model favored by the Canadian Paediatric Society (CPS) and recognized by Canadian courts takes shape in the complex normative environment of the NICU. Using empirical research on decision-making in the NICU published in secondary sources, I will draw attention to the processes whereby parents and neonatologists accommodate the demands and limits of formal legal rules to the reality of neonatal critical care. To do so, I will base my analysis on the following research questions:

- How do parents and health care professionals use existing legal rules of surrogate decision-making in light of their lived experience in the NICU?
- What do lived experiences tell us about the adequacy of formal law to address the needs of surrogate decision-makers in pediatrics?

Informed by Martha-Marie Kleinhans and Roderick Macdonald's work on critical legal pluralism[5] and explained in chapter 1, my reflection on the shared decision-making

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[4] Martha-Marie Kleinhans & Roderick A. Macdonald, *What is a Critical Legal Pluralism?* (1997) 12 Can J L & Soc 25 at 25 (abstract).
[5] *Ibid.*

model will be anchored by an assessment of formal legal rules applicable to surrogate decision-making in pediatrics and reviewed in chapter 2. Following chapter 2's review of the law in theory, chapter 3 will delve into the lived experience of parents of critically ill infants in neonatal intensive care. Using testimonies of experience in the NICU found in various empirical research projects, Chapter 3 will provide examples of legal pluralism in practice in the NICU context. Chapter 4 will then critically reflect on the construction of informed consent and ethical dilemmas in a manner that excludes parental participation while confirming medical authority. This redefinition of roles within the framework of shared decision-making will lead into an analysis of the juridical implications of legally plural interactions in the NICU. Chapter 5 will reflect on the emergence of plural law in the neonatal context with a view to highlighting implications of excluding the normative voice of parents from the day-to-day medical decision-making concerning critically ill newborns.

Chapter 1: A Theory of Legal Puralism

1.1 Toward Legal pluralism

Health care and internormativity

The health care delivery environment has long been considered of particular interest for sociologists studying internormative phenomena.[6] As with any large bureaucratic organization, the hospital appears to the social science researcher as a social microcosm comprised of a distinct institutional culture and cohabitating sub-cultures.[7] Inside the hospital, sub-cultures associated with different professional groups must contend not only with each other but also with a wide range of outside influences embodied in patients, families, the cultural foundations of society, public services, insurance providers, scientific research, health policy and positive law. [8] The neonatal intensive care unit is one of these sub-cultures, simultaneously informing and transforming the institutional environment of the hospital.

Against the backdrop of a sociologically complex normative landscape where multiple - and sometimes competing - normative forces come into contact, legal

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[6] "Internormativity" is defined as "…l'ensemble des phénomènes constitués par les rapports qui se nouent et se dénouent entre deux catégories, ordres ou systèmes de normes." André-Jean Arnaud *et al.* (eds.), *Dictionnaire encyclopédique de théorie et de sociologie du droit,* 2d ed., (Paris : L.G.D.J.-E.J.A, 1993) at 314-314 *s.v. Internormativité.*

[7] Guy Rocher, "Les 'phénomènes d'internormativité': faits et obstacles" in Jean-Guy Belley, ed. *Le droit soluble: contributions québécoises à l'étude de l'internormativité* (Paris : L.G.D.J., 1985) 25 at 29.

[8] *Ibid.* See also Jean-Guy Belley, "Réactifs, activation, phase et produits" in Jean-Guy Belley (ed.), *ibid.* at 22; Ruth Murbach, "Le SIDA, le danger et le risque : quelques effets normatifs d'un fait social", *ibid.* at 43.

scholarship in neonatal intensive care revolves around the application of state-made law to extremely sick newborns.[9] However, the NICU environment challenges legal theory to address normative influences that fall outside the traditional meaning of law understood as formal rules created and executed by the State.[10] Legal pluralism, with its willingness to look beyond the black letter of the law, appears as a theory of choice to frame the decision-making process engaging parents of critically ill newborns and health care professionals. The following sections present an overview of the progression of legal theory from legal positivism to legal pluralism and a reflection on their limits and relevance to the study of shared decision-making in neonatal intensive care.

Legal Positivism

Born of the utilitarian understanding of law exposed by English jurist John Austin, the positivist doctrine is now generally associated with the ideas of H.L.A. Hart in *The Concept of Law*.[11] In *The Concept of Law,* Hart isolates three doctrines constitutive of the jurisprudential tradition of utilitarian thinkers Austin and Bentham: the separation of law and morals; the necessity to understand the distinctive vocabulary of law to understand its nature and function; and the imperative theory of law seeing it as "essentially a command."[12] Hart's work in *The Concept of Law* takes to task the

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[9] For instance, legal scholarship on neonatal intensive care has aimed at questions of best interest (see e.g. Hurlimann, *infra* note 87) and consent (see e.g. Barney Sneiderman, "A Do Not Resuscitate Order for an Infant Against Parental Wishes: A Comment on the Case of *Child and Family Services of Central Manitoba v. R.L. and S.L.H.*" (1999) 7 Health Law Journal 205.)

[10] For the purpose of my thesis, the term "State" is meant to include its agents, institutions and other public entities.

[11] H.L.A. Hart, *The Concept of Law* 2d ed. (Oxford: Oxford University Press, 1994) [Hart, "The Concept of Law"].

[12] H.L.A. Hart, "Positivism and the separation of law and morals" (1958) 71 Harv Law Rev 593 at 601 [Hart, "Separation of Law and morals"].

imperative theory by explaining how its over-simplicity does not reflect the variety of law found in the modern state.[13]

Yet, Hart's work should not be seen as a critique of Austin and Bentham's imperative theory but as an expansion of its application to the modern legal system.[14] What should be remembered for the purpose of understanding legal pluralism is Hart's limitation of the concept of law to rules issued by "individuals holding readily identified positions (such as that of sovereign or judge)" to the exclusion of other sources of obligation such as morality and etiquette. [15] Hart's positivism is particularly firm in its exclusion of morality from the scope of law. In Hart's view, law and morals may have common grounds such as the maintenance of social order, but it is fortuitous and inconclusive. If a legal system may exhibit some "specific conformity with morality," it does not follow that law must conform to the demands of morality or justice to be legitimate.[16]

Given Hart's focus on the distinction between law and morals – or between "what law is" and "what law ought to be" – it is not surprising that some of Hart's most famous critics came in response to this distinction. Lon Fuller's reply to Hart's argument laid the groundwork for legal pluralism by advocating an enlargement of the concept of law to include not only the reality described by the word "law" but also its inner

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[13] Hart, "The Concept of Law" *supra* note 11 at 31-32.

[14] *Ibid.* at 79-99.

[15] Hart's legal positivism defines law as the interplay of "primary rules" – or obligations-generating rules – and "secondary rules" – or "rules of recognition" which purpose is to ascertain and define the primary rules they serve. See also Lon L.Fuller, *The Principles of Social Order,* edited by Kenneth I. Winston (Durham: Duke University Press, 1981) at 13 [Fuller, "Principles of Social Order"].

[16] *Ibid.* at 183.

workings. Brought back to the analysis of shared decision-making in neonatal intensive care, if Hart's legal positivism allows the study of parental roles in Canadian law and jurisprudence, it would return questions about the interface of law, ethics and medical normativity to the realm of social sciences. The positivist lens would not stop to consider normative interactions as within the purview of legal scholarship.[17]

Fuller's interactional theory

To Fuller, it is not enough to preserve the integrity of the concept of law by merely describing what it isn't or shouldn't be. A proper definition of law must also concern itself with the obligation of fidelity to law or what makes subjects of the law follow it: "In its concern about assigning the right labels to the things men do, [legal positivism] seems to lose all interest in asking whether men are doing the right things" laments Fuller. [18] The acceptance of rules by those to whom they apply is rooted in a general sense that they are necessary. As such, fidelity to law is an ideal for which we plan through legislation generally believed to be right, good and necessary. At this fundamental point, law doesn't merely "intersect" with morality – as Hart believes – but *merges* with it.[19] For that reason, a standard must shape the development of law into socially acceptable legal norms otherwise the pursuit of justice and good order is purely accidental and cannot be described systematically through legal theory.[20] Fuller describes this necessary standard as

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[17] In fact, the failure to distinguish law from other "non-legal" forms of social ordering (viewed as within the purview of social sciences) still figures prominently amongst critiques of legal pluralism. See Brian Z. Tamanaha, "The Folly of the 'Social Scientific' Concept of Legal Pluralism" (1993) 20 J. L. & Soc'y 192.

[18] Lon L. Fuller, *Positivism and Fidelity to Law – A Reply to Professor Hart,* (1957) 71 Harv Law Rev 630-657 at 643 [Fuller, "Fidelity to Law"].

[19] *Ibid.* at 639-42.

[20] Fuller describes "good order" as "… a functioning order, and such an order has to be at least good enough to be considered as functioning by some standard or another." He does not, at that point, associate good

"the internal morality of law" and illustrates it by giving the example of a monarch whose word is the only law known to his subjects:

> He is, however, a dissolute and forgetful fellow, who never makes the slightest attempt to ascertain who have in fact followed his directions and who have not. As a result, he habitually punishes loyalty and rewards disobedience. It is apparent that this monarch will never achieve even his own selfish aims until he is ready to accept that minimum self-restraint that will create meaningful connection between his words and his actions.
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> …
>
> Law, considered merely as order, contains, then, its own implicit morality. This morality of order must be respected if we are to create anything that can be called law, even bad law. [21]

For Fuller, the positivist theory is fundamentally flawed in its attempt to limit law to its reflection on human experience ("what law is"). By recognizing that law makes some behaviors non-optional, even the positivists recognize law's internal morality by referring to a standard of behavior ("what law ought to be"). Moreover, law is not only subservient to its internal morality; the authority to make law "must be supported by moral attitudes that accord to it the competency it claims."[22] This morality, "external to law," not only legitimizes legal constraints on individual behavior but also enables judges to realize their duty of fidelity to law – and to judge fairly – by making the law "as it ought to be."[23]

Following our journey of ideas from positivism to legal pluralism, Fuller's contribution to legal pluralism might not be immediately obvious from his thoughts on

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order to a particular conception of morality but to the notion of "standard" present in any functioning government, be it democratic, Fascist or Communist. *Ibid.* at 644.

[21] *Ibid.* at 644-45.

[22] *Ibid.* at 645.

[23] *Ibid.* at 647.

the merger of law and morality. However, by stretching the concept of law to include not only how law is but how "law ought to be", Fuller offers a pluralist outlook by questioning not only the phenomenon of law in human interactions but the bases of its legitimacy and the social processes by which rules are created. Fuller thought that to be able to understand "the moral and psychological forces that underlie law generally and give it efficacy in human affairs," law should be construed broadly to include "not only the legal systems of states and nations, but also the smaller systems – at least "law-like" in structure and function – to be found in labor unions, professional associations, clubs, churches, and universities." [24] In *Human Interaction and the Law*, Fuller pursues his journey toward legal pluralism and tackles the common processes between customary law and state-made law. He finds a common denominator to every legal system, be it made of enacted, customary or managerial laws, in a shared purpose as a "language of interactions" whereby lawgivers and subjects of law establish "stable interactional expectancies."[25]

While Fuller refers to the interactional foundations of enacted (formal) law, *Human Interaction and the Law* makes similar claims about customary law, contract law – the law created by a contract rather than the law *of* contracts – and common law adjudication. If Fuller makes no allusion to the multiplicity of legal orders targeted by legal pluralism[26], he stretches the confines of "the law" to include interactions between

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[24] Lon L. Fuller, *Human Interaction and the Law*, (1969) 14 Am J Jurisprud 1 at 1 [Fuller, "Human Interaction and the Law"].

[25] *Ibid.* at 2 and 24.

[26] *Human Interaction and the Law* poses human interactions as *law creating* but law is still understood as something palpable, *reified* through custom, legislation, adjudication or contract. Socio-legal scholars interested by legal pluralism such as John Griffiths and Roderick MacDonald have objected to such reification.

legal subjects and legislator. Created by interactions, law is now defined above and beyond an exercise of authority and gains legitimacy from general acceptance. As such, law not only loses its *vertical* dimension from state to subject but takes on a new texture. Combined with Fuller's previous thoughts on the internal morality of law, we can conclude that the processes whereby citizens organize their interactions with each other and with the state are driven by a sense that such organized interactions are right, good and necessary. This shape and texture of law, growing from the ground up and built of what legal subjects believe to be in society's best interest, is what I wish to take from Fuller and bring to my analysis of legal pluralism.

Legal Pluralism as a descriptive conception of law

Legal pluralism was born of a critique of legal positivism following the general lines of questioning adopted by Fuller in his reply to Hart. In an attempt to describe legal pluralism, John Griffiths starts with the intellectual context of legal pluralism as inherited from the "liberal hegemony of the last few centuries" whereby "law is and should be the law of the state, uniform for all persons, exclusive of all other law, and administered by a single set of state institutions."[27] Because the "centralist"[28] doctrine of law is so pervasive and, to some extent, a corollary to political liberalism,[29] the concept of law as flowing from the top down within a political organization has permeated socio-legal studies to the point where it has become the only concept of law available to social scientists.[30] Socio-

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[27] John Griffiths, *What is Legal Pluralism?* (1986) 24 J. Legal Pluralism & Unofficial L. 1 at 3 [Griffiths].

[28] Griffiths uses the term "legal centralism" or "centralist doctrine" to describe what Hart and Fuller termed "legal positivism" or "positivistic doctrine" described above at 11-12.

[29] Griffiths, *supra* note 27 at 3.

[30] Concerns about the axiomatic nature of socio-legal scholarship are expressed throughout academic literature on legal pluralism. For examples, see Belley in Belley (ed.) *supra* note 8 at 7; Rocher in Belley (ed.) *ibid.* at 25; Roderick MacDonald, "Les Vieilles Gardes. Hypothèses sur l'émergence des normes,

legal empirical research has consequently been built on ideas accepting legal centralism either wholeheartedly or with reservation, but never challenging its basic assumptions.[31]

The confusion between what law is and the theory of what law should be has not only been reflected in the one-dimensional quality of socio-legal scholarship, it has also hindered the accurate observation of the phenomenon of law by assuming that "legal reality, at least in 'modern' legal systems, more or less approximates the claims made on behalf of the state."[32] However, the daily reality of resistance to state law points toward a gap between law and behavior that should, according to Griffiths, be investigated critically instead of constantly re-discovered by social scientists.[33] For Griffiths, this repeated discovery of law as "plural rather than monolithic" proves that legal centralism is a myth. "Legal pluralism is the fact" he writes.[34]

Griffiths pursues his description of legal pluralism by presenting how certain forms of pluralism have appeared within the framework of the centralist doctrine. "Weak" pluralism appears when the sovereign "validates different bodies of law for different groups in the population" as a "technique of governance on pragmatic grounds."[35] This type of pluralistic influence is often found in colonial and post-colonial situations where pre-existing customary law is allowed to co-exist with the state legal system or

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l'internormativité et le désordre à travers une typologie des institutions normatives" in Belley (ed.) *ibid.* 233 at 242; André-Jean Arnaud, "From limited realism to plural law: normative approach versus cultural perspective" (1998) 11 (3) Ratio Juris. 246 at 246; Jean Carbonnier, *Flexible droit: Pour une sociologie du droit sans rigueurs,* (7 ed.) (Paris: L.G.D.J., 1992) at 87; Guy Rocher, *supra* note 7 at 123-127; Boaventura De Sousa Santos, "Law: A Map of Misreading. Toward a Postmodern Conception of Law" (1987) 14 J. L. & Soc'y 279 at 280.

[31] Griffiths, *supra* note 27 at 3.

[32] *Ibid.* at 4.

[33] *Ibid.*

[34] *Ibid.*

[35] *Ibid.* at 5.

recognized as being part of it. Yet, since these parallel legal regimes exist within the overarching control of the state, they are still conditional upon recognition and validation by the central power. Moreover, these pluralistic influences are likely to be judicially limited in their application, their scope and the circumstances of their operation. As such, they do not depart significantly from the idea that law ultimately depends upon a single validating source.[36]

Griffiths' analysis continues with a perusal of the academic literature pertaining to legal pluralism. His dismisses most socio-legal descriptions of legal pluralism as concerned with the way in which legal pluralism inserts itself in the national legal system, making it *de facto* a feature of state law and confirming the stranglehold of legal positivism on descriptive legal theory.[37] One important insight of Griffiths' critique of legal pluralism as presented by socio-legal scholars is his insistence that state recognition of legal pluralism – as is the case when pre-colonial customary law is recognized by a colonial legal system – "is not a prerequisite to the empirical existence of a legal order."[38] He continues by excluding definitions of legal pluralism contingent to the co-existence, within a legal system, of different legal "mechanisms" applicable to similar situations. Such descriptions, once again, make legal pluralism dependant on state law's recognition of its existence and the attribute of clearly definable groups within the legal system. For Griffiths, legal pluralism in the "weak" sense is nothing more than a variation on legal

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[36] *Ibid.* 5-8. Examples of conceptions of legal pluralism limited to the interaction of normative orders and state law can be found in Sally Engle Merry, "Legal Pluralism" (1988) 22 (5) Law Soc Rev 869.

[37] Griffiths critical insight focuses on the contribution of M.B. Hooker, John Gillisen and Jacques Vanderlinden to socio-legal scholarship. *Ibid.* at 9-14.

[38] *Ibid.* at 12. This is also the most contentious point of his reasoning, see e.g. Brian Z. Tamanaha,*supra* note 17. Tamanaha accuses "legal pluralists" – and Griffiths at their helm – of confusing law with social life.

centralism and does not challenge its underlying assumptions about the origins and justification of power.

Where, I believe, Griffiths' analysis is particularly relevant to the study of surrogate decision-making in ethically charged matters is in the blurring of the geographical, cultural and political lines of the legal orders objects of pluralism. By defining law as a social phenomena rather than an exercise of power, Griffiths allows law to occur regardless of whether or not the subjects of law can be defined according to pre-existing categories such as religion, geography, economic status or ethnicity.[39] Inasmuch as legal pluralism can be predicated from a social group and inasmuch as the empirical existence of the legal phenomena is enough to identify a legal order, it follows that legal pluralism allows the inclusion of normativity into the scope of law.[40] Accordingly, the experience of normativity originating from one's moral principles, religious precepts or personal beliefs is as *legal* as that exerted by criminal statutes on one's actions even though the consequences of transgression are different. Normalized behaviors occurring between parents and health care providers at a newborn's bedside – that is, behaviors dictated by norms falling outside the limited purview of state law – can be analyzed as "law" based on their effect rather than on their origins.

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[39] By describing those to whom law applies as *subjects* of law, I am aware that in a pluralistic context, *subjects* of law are more accurately defined as *objects* of law. However, since legal subjectivity is more readily used in legal scholarship and since objects of law are also subjects of law, I decided to err on the side of clarity and refer to the objects/subjects of law in their subjective capacity.

[40] For the purpose of this thesis, "normativity" is conceived simply as a "means to end" relationship. Norms are what makes us act a certain way to reach a certain end. They can be imposed from outside the individual (e.g. religious commandments, criminal law, rules of a game) or from within (e.g. goals and aspirations, conscience, avoidance of pain, common sense.)

Because he is not satisfied by legal scholars' understanding of legal pluralism, believing it to assume the dominant model of law as defined by the state, Griffiths turns to anthropology's theories of legally pluralistic social structures. The turn to anthropology proves particularly beneficial by providing a descriptive theory of legal entities. Without it, legal pluralism remains, if interesting, ethereal and difficult to use as a descriptive theory of law. A descriptive theory of legal entities allows us to observe not only the production of normativity between legal subjects but also how the different legal orders present in a situation of legal pluralism interact with each other and with state law.[41] Griffiths' analysis of anthropological research on "legally pluralistic structures" retains Sally Falk Moore's concept of the "semi-autonomous social field" as a refined and appropriate tool to analyze legal pluralism.[42]

Sally Falk Moore's contribution to Griffiths' descriptive theory of legal pluralism is premised by a pervasive doubt that "fundamental social change can readily be brought about by means of legislation."[43] However, because she recognizes the instrumental role of law in the maintenance of social order, she assumes the empirical existence of law before defining the social entity from which it originates.[44] Falk Moore's inquiry posits that "the various processes that make internally generated rules effective are often also the immediate forces that dictate the mode of compliance or non-

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[41] While state law does not define law under a pluralistic lens, it is an undeniable normative force that legal subjects, even if considered broadly as taking part in the production of normativity in their daily lives, must contend with.

[42] *Ibid.* at 15 and 29-37.

[43] *Ibid.* at 29.

[44] This approach departs from the other socio-legal and anthropological approaches to legal pluralism considered by Griffiths whereby legal subjects are defined based on their incorporation into legally sanctioned entities. In other words, the empirical observation of legal pluralism occurs only after a legal entity has been defined according to its status within state law. Falk Moore's legal subjects are identified as legal subjects only after the existence of a legal phenomenon has been observed.

compliance to state-made legal rules."[45] It is by observing such legal processes that Falk Moore unpacks the notion of the "semi-autonomous social field" defined by its ability to generate rules and induce – or coerce – compliance rather than by its organization.[46] Because Moore's model of the semi-autonomous social field imposes no conclusions as to the "nature and direction of influence between the normative orders," it has endured as a generalizable and widely-used conception of plural legal orders.[47]

Where Moore's conception of legal pluralism is particularly relevant to the study of decision-making in the NICU is in its ability to shed light not only on the emergence of normativity outside the boundaries of state-made law but also on the normative interactions between social fields, including state-made normativity. As a result, Falk Moore's legal pluralism considers how decision-makers relate not only with each other but also with the more formal circle of enacted rules and guidelines. Using Moore's semi-autonomous social field as unit of observation, Griffiths concludes by offering the following descriptive theory of legal pluralism:

> A descriptive theory of legal pluralism deals with the fact that within any given field, law of various provenances may be operative. … A situation of legal pluralism – the omnipresent, normal situation in human society – is one in which law and legal institutions are not all subsumable within one system but have their sources in the self-regulatory activities of all the multifarious social fields present …[48]

Griffiths's descriptive theory of legal pluralism chooses to approach law through its manifestation in the social field. Griffiths' social-scientific approach is relevant to the

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[45] Sally Falk Moore, *Law as Process: An Anthropological Approach (1978),* (Hamburg: LIT, 2000) at 57.
[46] *Ibid.*
[47] Engle Merry, *supra* note 36 at 878.
[48] *Ibid.* at 38-9.

study of decision-making in the NICU because it extends the circle of law to the expression of normativity between decision-makers thus recognizing the influence of factors other than state law on the behavior of parents and health care professionals. However it does not offer a proper legal theory. For instance, it does not venture into the purpose of law, its legitimacy and its creation within the social unit; nor does it tackle the origins and purpose of legal subjectivity on an individual basis.[49] The limitations of Griffiths' legal pluralism are problematic for the study of decision-making in the NICU insofar as it sheds no light on the possibility that law may be created in units smaller than the semi-autonomous social field, for instance, in individuals such as parents or health care workers who do not have the ability to "generate rules and induce … compliance."[50] This is where Fuller's doctrinal approach to law as produced and legitimized through human interactions comes to complete Griffiths' conception. Efforts to integrate a self-standing legal theory to descriptive conceptions of legal pluralism have been attempted and the following section will analyze Martha-Marie Kleinhans and Roderick Macdonald's essay on "critical" legal pluralism.[51]

1.2 Critical Legal Pluralism and the creation of normativity

Exploring the boundaries of law

In his descriptive conception of legal pluralism, John Griffiths characterized the challenges facing legal pluralism as emanating from the inability of socio-legal scholars

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[49] Griffith readily admits that his conception of legal pluralism is not a legal theory, see *Ibid.* at 12: "Legal Pluralism is the name of a social state of affair … It is not the name of a doctrine, or a theory, or an ideology."

[50] See *supra* note 43.

[51] Kleinhans & Macdonald, *supra* note 4.

and social-scientific scholars to think of the manifestation of law in isolation from the dominating positivist legal theory. I ventured that Fuller's interactional theory could bolster Griffiths "conception" of a legally pluralist social field and turn it into a usable legal theory. The Fullerian influence on descriptive conceptions of legal pluralism can be studied through Kleinhans and Macdonald's ideas of a *critical* legal pluralism.

Kleinhans and Macdonald introduce the concept of a critical legal pluralism by asking what types of human interactions are to count as law. They posit that social-scientific legal pluralism, while signaling a "pervasive pluralism in law," still objectifies and reifies the cultural form of law by placing it in the "normative vacuum" between legislator and subject.[52] As a result, the social-scientific community still defines normativity – or plural law – in relation to state-made law but does not offer a compelling theory explaining the origins and legitimacy of law.[53]

The authors' intellectual enterprise seeks to explore the boundaries of law – already blurred by the social-scientific approach – by locating the creation and

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[52] Kleinhans and Macdonald's objections to social-scientific legal pluralism may not be entirely due to the insufficiency of its theoretical underpinnings. Franz Von Benda-Beckmann suggests that there is a wide-spead lack of appreciation among legal and anthropological scholars for the differences in purpose and limitations of each other's academic enterprises. See Franz Von Benda-Beckmann, "Who's Afraid of Legal Pluralism?" (2002) 47 J. Legal Pluralism & Unofficial L. 38 at 41.

[53] Kleinhans & Macdonald, *ibid.* at 27 and 35-6. This point is essential to Kleinhans and Macdonald's critical legal pluralism and bears further clarification. The authors argue that by placing legal pluralism's object of study where law isn't, the social-scientific community falls prey to the same axiomatic definition of law as legal positivists. Kleinhans and Macdonald's point can be illustrated using Boaventura de Sousa Santos "law as map" allegory (see de Sousa Santos, *supra* note 30). In "Law as a Map of Misreading," de Sousa Santos argues that law is to social reality what a map is to spatial reality: it needs to distort or represent reality using scale, projection and symbolization to fulfill its function. At 285, de Sousa Santos pursues his argument with the description of a map of the ocean without land masses such as islands or capes: to be usable, the map needs to represent selected features and details of reality. Failure to do so, in the case of the ocean, will yield a blank map. Land masses or astronomical references are necessary to navigate using a map of the ocean. Kleinhans and Macdonald criticize social-scientific legal pluralism for placing plural law in the ocean between the land masses of formal law but failing to explain what the land masses are, why they are on the map and why they should be relied on as an accurate reflection of the reality.

manifestation of law at the level of the legal subjects rather than in the co-existing legal orders. For Kleinhans and Macdonald, a critical insight into legal pluralism presents the structures of law and legal subjectivity as created by the subjects rather than determined by social factors, be they the semi-autonomous social field or the empirical manifestation of the normativity. Because a critical legal pluralism neither "cleaves to an hypothesized plurality of empirically discoverable normative orders nor is it transfixed upon assessing their status as legal or non legal objects of inquiry [,]" it permits a critical reflection not only on the production of normativity but also on its "moral starting point".[54] Once the legal subject is conceived as the starting point of normativity, we witness a gradation – as opposed to delineation - of plural law. Law emerges in the imagination of the subject before interacting with other forms normativity located with other subjects or institutions.[55] These interactions contribute to the apparition of the interactional norms and expectancies eventually expressed through formal law. Accordingly, Kleinhans and Macdonald dismiss any attempt to delineate state law and normativity as a purely semantic. While the political organization of social life requires the delineation of what will figure as law and what will remain mere normativity, Kleinhans and Macdonald do not believe that such political delineation reflect an existing superiority of law "properly so-called" over self-created normativity and internormativity.[56] By shifting the focus of the legal phenomena to the subject of law, a critical legal pluralism provides an ultimately relevant framework to the study of decision-making in the rugged normative landscape of a neonatal intensive care unit.

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[54] *Ibid.* at 38.

[55] In this sentence, I use the word "imagination" as (1) the ability to visualize, to form images and ideas in the mind, and (2) the part of the mind where ideas and thoughts are formed. I do not suggest that the creation of normativity is a creative act similar to literature where a semblance of reality is represented: I believe that law is rooted in reality rather than merely representative.

[56] *Ibid.* at 42.

Critical Legal Pluralism in Neonatal Intensive Care

The relevance of a critical legal pluralism to the study decision-making in the NICU appears from several angles. First, by locating the concept of law with the legal subject rather than with a sociological unit of observation such as the semi-autonomous social field, Kleinhans and Macdonald's critical legal pluralism does not require the empirical demonstration of the existence of a social field prior to the study of the legal phenomenon. Accordingly, my analysis of decision-making in the NICU will not delve into the identification of sites of normativity such as "the family" versus "the doctors" or "the religion" versus "the union," but seek to understand the locus of obligations regardless of their origin. This dislocation of the legal phenomenon, first from the positivist understanding of law and then from the social-scientific field to place it finally with the legal subject, will allow me to include parental experiences of normativity at their child's bedside within the circle of law and redefine each decision-making agent as a legal order existing within a legally pluralistic structure. Given the scope and magnitude of decisions made in neonatal intensive care, where questions about basic care can have life and death implications, as well as the swift tempo commanded by these decisions, the benefits of extending the circle of law to self-created normativity will be felt in the ability to consider legal obligations "properly-so-called" and moral or ethical obligations on equal footing under the banner of "law."

Relocating law at its normative genesis avoids giving more legitimacy to forms of law claiming state-sanctioned coercion at the exclusion of forms of law which are self-created, self-imposed and self-enforced. In the context of ethical decision-making in the

NICU, Kleinhans and Macdonald's critical legal pluralism gives leave to conceive normativity at the infant's bedside as a Venn diagram where strictly legal obligations, morality, ethics and professional integrity figure as overlapping sets. The image of law thus produced reflects the intricate fabric and the intensity of internormative conflicts in intensive care in a manner that traditional legal scholarship can only partly represent. Finally, the emphasis placed by critical legal pluralism on the constitutive aspect of law sheds light on the potential of self-created normativity either to respect or resist state law. Returning to Fuller's "internal morality of law," we see that resistance to state-made law eventually influences the production or legitimization of the legal instrument. A critical legal pluralism not only reveals a new way to know the world through law but also glimpses into the future and evolution of law. The effects and implications of dynamics of compliance and resistance for the evolution and legitimization of formal law will be discussed in greater details in the last chapter of this thesis. The step from legal theory to the development of sound health policy is one that I take willingly. The next section will look into the relevance of legal pluralism for the study of interactions in the NICU.

Interactions in the NICU: Pictures of a Rugged Landscape

When parents and healthcare workers engage in shared decision-making at an infant's bedside, the interaction of formal legal obligations – obligations defined by state-made law– and moral obligations – obligations arising from one's sense of right and wrong – creates an intricate normative fabric. This fabric appears without necessarily revealing its point of origin or its general direction. The advantages of legal pluralism for the study of internormativity in the NICU can soon become its downfall: in seeking to avoid the reification of the interactions that are to count as law, it can leave us with nothing but an insubstantial notion of legal autopoiesis.[57] If we should not reify the social field from which normativity arises to avoid denying the existence of the legal phenomena outside pre-conceived fields of normativity, so it remains that a manageable unit of study must be determined if this thesis is to have a beginning, a middle and an end. Without claiming to identify the genesis of normativity, an appropriate unit of study should serve as a magnifying glass highlighting an area of normativity rather than a cookie-cutter setting firm boundaries as to what is *in* and what is *out.* I propose to use David M. Engel's concept of *domain* as developed in his contribution to Sarat and Kearns' *Law in Everyday Life*: "Law in the Domains of Everyday Life: The Construction of Community and Difference." [58]

Engel's *domains* offer a way of thinking about law that recognizes its ability to define and be defined by everyday life. Because it emphasizes the "*processes* that characterize the … fluidity, negotiability, and ever-changing qualities of both law and everyday life[,]"[59] Engel's domain presents as an ideal complement to Kleinhans and Macdonald pluralistic approach. Engel's observations echo Kleinhans and Macdonald's concerns about conceptions of law that reflect or confirm its hegemony over everyday life and warn against the temptation to conceive sites of normativity as "phenomena of the

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[57] "Autopoiesis" is a biological term defining a process whereby a system, organization, or organism produces and replaces its own components and distinguishes itself from its environment. Online: Encarta Dictionary MSN < http://encarta.msn.com/dictionary_701704423/autopoiesis.html> [Accessed January 08 2008]; see also Kleinhans & Macdonald, *supra* note __ at 42 on the "autopoietic approach" to legal pluralism.

[58] Austin Sarat & Thomas R. Kearns, eds., *Law in Everyday Life* (Ann Arbor: University of Michigan Press, 1995) [Sarat & Kearns] at 123-170.

[59] *Ibid.* at 126.

natural world like towns or forests and that we only need to ‘go there’ to conduct our research.”[60]

To grant domains enough flexibility to adapt to a broad-based definition of law, Engel defines them according to four aspects: actors, time and space, community and norms. Actors within a given domain are located in a social matrix by time and space and shaped around concepts of inclusion, exclusion, shared value and purpose. These concepts may be spatially defined but are more accurately defined by the concept of community. The interactions of actors within domains create patterns of interaction and normative expectations that “guide future behavior, facilitate exchanges, process disputes and even structure hostilities.”[61] Building on those four cornerstones, my thesis proposes to define its area of analysis around the normative interactions of parents and healthcare workers as they come together to make decisions in the best interest of critically ill patients in the neonatal intensive care unit. The normative framework presiding over my analysis will be defined by the Canadian Paediatric Society (CPS)’s position statement on treatment decisions regarding infants, children and adolescents[62] and by the normative interactions occurring between the CPS’ normative framework and pre-existing normative obligations such as morality, ethics, professional integrity and culture.

Without further refining the scope of normative interactions found in the NICU, shared decision-making will prove to cast a very wide net: the day-to-day medical care of

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[60] *Ibid.* at 128.
[61] *Ibid.* at 133, paraphrasing Fuller in “Human Interaction and the Law,” *supra* note 24.
[62] Canadian Paediatric Society, “Position Statement B-2004-01: Treatment decisions regarding infants, children and adolescents,” online: <www.cps.ca/english/statement/B/b04-01.pdf > accessed October 15, 2007 [CPS Statement].

intensive care patients is composed of a succession of decisions, mostly medical in substance, which may or may not have legal or ethical components and may or may not involve the direct acquiescence of the child's parents. Moreover, some legal constraints on the range of options available to parents and caregivers may limit their decision-making powers regardless of competing normative influences, as would be the case if parents and caregivers felt strongly that euthanasia was in the best interest of a particular child.[63] Because the focus of my research is the normative landscape of the NICU from a pluralistic perspective, I have decided to refine my domain of analysis even further by turning to the decision-making process as it stands facing ethical dilemmas or conflicts.

For the purpose of my research, I have retained the definition of "ethical decision-making" presented by Winifred Ellenchild Pinch in her research project on parental perception of ethical decision-making in the NICU.[64] Pinch's definition of ethical decision-making starts by a gradation of treatment decision-making going from "what is available and what is possible, who is involved, and then moves on to examine what *should* be done, why it should be done, and which decision ultimately prevails."[65] What I find particularly appealing in Pinch's gradation is the possibility of circumscribing the range of decisions under analysis by excluding treatment decisions that are medically impossible, unavailable, illegal – understood strictly - or somehow out of the reach of decision-making agents. Without denying the existence of bioethical exploration around questions of possibility, availability or legality of treatment, this thesis will be limited to

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[63] In Canada, euthanasia is not distinguished from homicide and constitutes a criminal offense under s. 222 of the *Criminal Code,* L.R. 1985, ch. C-26.
[64] Ellenchild Pinch, *supra* note 1.
[65] *Ibid.* at 22.

the investigation of internormativity as it arises from ethical decision-making where treatment options present practical – as opposed to theoretical – dilemma. Ethics preoccupies itself with the study of what is right, just and good and approaches right and wrong using philosophical enquiry. As a philosophical discipline, it posits that the love of wisdom will lead the open-minded thinker toward the right, the good and the just.[66] Accordingly:

> A bioethical dilemma is created when various solutions appear equally good or bad and priorities seem difficult, if not impossible, to set. Conflicts also arise when the people involved place significantly different values on the possible actions [citation ommited].[67]

From Pinch's observations, three distinct definitions appear: *ethical decision-making* covers decisions about what *should* be done for a particular infant and is concerned by the right, good, or just decision. Ethical decision-making includes, but is not limited to, decisions about withholding or withdrawing life-sustaining support. It may also address daily care that is painful and burdensome or that impedes proper palliative care. Ethical decision-making also includes, but should be differentiated from, the *ethical dilemma* where more than one option is right, good or just;[68] and the *ethical conflict* where different parties to an ethical query disagree on what is right, good or just; or when parties disagree on the relative importance of factors involved in the ethical decision-

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[66] Michael Slote, *Encyclopedia of Bioethics,* Revised Edition (New York: Simon&Schuster, 1995) *s.v.* "ethics".

[67] *Ibid.* at 25.

[68] In a seminar series where I was presenting my theoretical framework, a graduate student observed that if two options were equally good, there could be no dilemma. I do not think it is necessarily the case. When two treatment options are equally acceptable, both may show benefits in very different areas of care as would be the case if one treatment option allowed a child to breastfeed earlier whereas another caused less physical discomfort but impeded proper suckling. It should also be said that treatment options in NICU too often involve balancing two wrongs as would be the case if serious side effects of total parenteral nutrition (TPN) such as metabolic bone disease and TPN-associated liver disease developed before a child's digestive system was ready for breast milk or formula.

making process, for instance when parties disagree on the impact of facial dysmorphism on future quality of life when discussing withdrawal of life sustaining support.

The picture of decision-making composed of an *ad hoc* meeting of professional, legal and ethical obligations emerging from as many sources as there are parties to the decision-making process presents such a rugged and fragmented normative landscape that it may be hard to imagine how these normative influences can combine to yield a practicable result. However, the daily reality of decision-making in the NICU attests to its possibility, just as painting a mountainous landscape combines stormy elements with deadly peaks to produce a beautiful image.

1.3 Methodology

Because Canadian NICUs have not been the focus of extensive research I will rely on a variety of sources to conduct my analysis. The legal analysis of decision-making and standard of care will be conducted by researching Canadian legislation and jurisprudence as well as professional guidelines pertaining to pediatric decision-making. A critical overview of these guidelines will show to what extent they can be applied *mutatis mutandis* to the NICU environment. Research into the socio-legal organization of the NICU and the origins of normativity will rely on secondary sources, as will research on the challenges posed by neonatal medicine on the theory of standard of care. Because most of these sources are American, they will be compared to Canadian sources (insofar as they exist) to ensure that parallels can be drawn between Canadian and American sources and the limits of these parallels. Finally, research into parental experience of decision-making will draw from field research conducted mainly in the U.S. by sociology and anthropology scholars, particularly on two qualitative research projects conducted on the NICU environment: Renée Anspach's *Deciding Who Lives: Fateful Choices in the Intensive Care Nursery* and Winifred Ellenchild Pinch's *When the Bough Breaks: Parental Perception of Ethical Decision Making in the NICU*.[69] The testimonies found in these two studies will also be used to bolster my critical reflection on the normative landscape of the NICU and its impact on decision-makers.

Anspach's research project in *Deciding Who Lives* studies what she calls "life-and-death decisions." Anspach starting point is sociological and she embarks in a thorough analysis of decisions as social acts. Accordingly, the scope of her research, in terms of parental involvement, is limited to the actors involved in life-and-death decision-making. She notes that parents are rarely actively involved in decision-making but that their attitude at the infant's bedside influences treatment decisions made by health care professionals. Accordingly, inasmuch as parental voices are excluded from life-and-death decisions, they are also excluded from Anspach's research purview. Pinch, on the other hand, studies parental perceptions of ethical decision-making in the NICU and does not dwell so much on whether parents are involved in ethical decision-making but how they perceive their involvement. Like Anspach, Pinch reports an absence of parental involvement in ethical decision-making and concludes, through the voice of her research subjects, that parents do not perceive themselves as decision-makers while their child is in intensive care. If both research projects offer interesting but limited insight into everyday

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[69] Renée R. Anspach, *Deciding who lives: Fateful choices in the intensive care nursery* (Berkeley: University of California Press, 1993) [Anspach]; Pinch, above note 1.

life in the NICU, they foster critical thinking about parents and families in the Canadian NICU context. Anspach and Pinch' research point toward avenues of empirical inquiry in the Canadian context, looking for instance at parental influence in a context of multi-culturalism, the normative influence of universal health care funding on life-and-death (or ethical) decision-making in the NICU and the normative environment of the Canadian NICU.

Chapter 2: Shared Decision Making in Pediatrics

The analysis of decision-making in NICU from a legally pluralist perspective posits that the concept of law extends beyond enacted law to include normative influences. Normative influences are forces that direct human behavior.[70] Normative influences are conceptualized as located *within* the legal subject and shape behaviors in no lesser way than the coercive power of state law, arguably located *outside* the legal subject. Such normative influences, conceived as legal orders or "circles"[71], interact at every level of human activity and create expressions of law generally ignored by legal scholarship. At the level of normative interactions, law emerges when distinct normative orders enter into contact with each other, not necessarily in a head-on collision but more often as gears fitting within one another.[72]

Recognizing that the object of legal pluralism lies beyond enacted law does not deny the palpable coercive effect of formal law on everyday lives. Formal (enacted) legal norms organizing medical decision-making and the applications of surrogate decision-making exert an appreciable influence on the behavior of decision-making agents,

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[70] See *supra* note 40.

[71] Kleinhans & MacDonald, *supra* note 4 at 45.

[72] An exhibit at the Science & Technology Museum in Ottawa seeks to explain the effect of gears and poulies to children (and often to parents as well). This exhibit offers an interesting imagery to explain the dynamics of internormativity as a legal phenomenon. On the left hand side of a meter-long horizontal pane is a crank turning a set of gears. Each gear is involved with the next one so that turning the crank puts all the gears in action simultaneously. At the end of the set is a bird with mechanical wings. The children are asked to study the interacting gears before turning the crank and say which way they should turn the crank to make the bird fly forward. The challenge lies in the varying size and orientation of the gears which change the direction of the gears – clockwise or counter-clockwise – several times between the crank and the bird. Taking the mechanical bird as the end of internormativity, the interest of legal pluralism is not so much to determine which way the bird *should* go but rather, which way the bird *is* going once all the interacting normative orders are taken into consideration and recognized as legitimate sources of law.

whether this influence is felt passively or actively.[73] While arguing for the enlargement of the concept of law to include normative orders such as social organization, church or culture, I want to place formal legal guidelines at the starting blocks of my pluralist critique. If the pluralist critique advocated by Kleinhans and MacDonald warns against defining legal orders in strict relation to state law – as opposing, confirming or merely filling its interstices – it remains that the expression of normativity will either defy, confirm of facilitate the application of formal law.[74] As such, formal law provides a contrasting backdrop against which normative interactions can be observed and defined.

Principles of decision-making applicable to neonatal intensive care in Canada are the same as those applicable to general pediatric medicine. The broad lines of surrogate decision-making in pediatrics branch out to recognize the varying degrees of needs, abilities and independence characterizing legal minority. The following chapter proposes an initial overview of pediatric decision-making in Canada with a particular focus on the shared decision-making model favored by the Canadian Pediatric Society in its position statement on treatment decisions for infants, children and adolescents.[75] I will use a two-pronged approach to highlight how normative interactions between parents and health

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[73] The distinction I make between "active" and "passive" influence relates to the degree of similarity between the enacted rule and an individual's perception of what should be done. For instance, the coercive effect of legal surrogacy will be felt more strongly (actively) by a family who thinks that life-and-death decisions should be made by a community elder or religious leader than by parents who believe themselves to be best placed to make medical decisions on behalf of their child in accordance with Canadian law and health policy. The same observation can be made about the jurisprudential definition of best interest and its coercive effect on parents for whom best interest is defined by different factors than those chosen by the courts.

[74] This point will be developed in more depth in the fifth chapter of this thesis. See also Roderick Alexander MacDonald *Lessons of Everyday Law* (Montreal: McGill-Queen's University Press, 2002) at 40. For an illustration of the interaction between formal law and everyday customs facilitating its application, see Lon L. Fuller, "The Law's precarious hold on life" (1968) 3 Ga. L. Rev. 530 [Fuller, "Law's precarious hold on life"].

[75] *Supra* note 49 (ch.1)

care professional act to curtail parents' decision-making authority at their infants' bedside. First, it will conduct a summary analysis of the formal law applicable to pediatric decision-making (Chapter 2). Following this analysis, it will use social-scientific empirical research conducted in NICU to illustrate the gap between the role given to parents by law and the authority they are allowed to exert in day-to-day decision-making (Chapter 3 and 4). The present chapter posits that medical norms of therapeutic success and best interest undermine the pluralist underpinnings of formal law and limit parental agency in surrogate decision-making.

2.1 Deciding on behalf of children: Surrogate decision-making in Canadian law

Capacity

While medical decision-making occurs in all therapeutic encounters, the challenges of medical decision-making in pediatrics stem largely from children's incapacity to give informed consent to medical treatment required by their state of health. Legal majority, the age at which children are perceived as having become capable legal subjects, is defined by provincial legislation and varies between 18 and 19 years of age.[76] However, law recognizes that if children from birth to late teens fall into a single legal category ("minors"), their needs, abilities and degree of independence vary widely. As

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[76] Majority occurs at 19 years of age in British Columbia (*Age of Majority Act,* R.S.B.C. 1996, c. 7 s. 1), New Brunswick (*Age of Majority Act,* R.S.N.B. 1973, c. A-4 s. 1) , Newfoundland and Labrador (*Age of Majority Act,* S.N.L. 1995 c. a-4.2 s.1), Nova Scotia (*Age of Majority Act,* R.S.N.S. 1989. c.4 s.2) , the Yukon (*Age of Majority Act,* R.S.Y. 2002 c. 2 s.1), Nunavut and the Northwest Territories (Both *Age of Majority Act,* R.S.N.W.T. 1988 c. A-2 s.2); and at 18 years of age in all other provincial jurisdictions: *Age of majority Act*, RSA 2000, c. A-6 s. 1 (Alberta), *Age of Majority Act,* CCSM c. A-7 s.1 (Manitoba), *Age of Majority Act*, R.S.P.E.I. 1988, c. A-8 s.1 (Prince Edward Island), *Age of Majority Act,* R.S.S. 1978, c. A-6 s.2 (Saskatchewan), *Age of Majority and Accountability Act,* R.S.O. 1990, c. A-7 s.1 (Ontario), Art. 153 C.C.Q. (Québec).

with majority, “capacity” is a legal construct referring to a person’s ability to understand the information relevant to make an informed choice.[77] In the context of health care interventions for people under 18 or 19, the capacity to give informed consent is defined in part by the person’s age but also by her cognitive ability “to appreciate the reasonably foreseeable consequences of [her] decision.”[78] Law’s attempt to recognize children’s varying cognitive capacity within minority takes shape though the “mature minor” doctrine whereby minors can, in some circumstances, consent to medical treatment without the knowledge or permission of their legally recognized proxies.[79] Born of the Common Law, the “mature minor” is also recognized by some provincial statutes allowing minors to consent to health care intervention once their cognitive capacity has been ascertained.[80] Otherwise, children do not possess the legal capacity to consent to medical treatment and must do so through the intermediary of a surrogate decision-maker.

In the Civil Law tradition of Quebec, consent to care given on behalf of minors must be separated between, on the one hand, care required by the state of health of the minor and care not required by the state of health of a minor, and on the other hand, minors aged under 14 or 14 and over. Consent to care required by the state of health of a minor is given by the person having parental authority or by the minor’s tutor.[81] Minors aged 14 or over can consent alone to care required by their state of health but their parents

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[77] Joan M. Gilmour, “Children, Adolescents, and Health Care” in Jocelyn Downie, Timothy Caulfield & Colleen Flood, eds, *Canadian Health Law and Policy*, 2nd ed., (Markham: Butterworths, 2002) 205 at 206.

[78] *Re Koch,* (1997), 33 O.R. (3d) 485 (Gen. Div.) (Q.L.). See also CPS Statement *supra* note 62 at 2.

[79] *Supra* note 76 at 211.

[80] *Ibid.* at 210. See also: Edward Etchells *et al.* “Bioethics for Clinicians: 3. Capacity” (1996) 155(6) Can Med Assoc J 657 at 658 (Table 1: Age of Consent for Medical Treatment in Canada). See also art. 14 C.C.Q. (minors aged 14 and older can consent to care required by their state of health); *Medical Consent of Minors Act,* S.N.B. 1976, c. M-6.1 s. 2 (minors aged 16 and older can consent to medical treatment if they have the capacity to understand the nature and consequences of the medical treatment).

[81] *Civil Code of Quebec*, 1991, C.-64, s. 14.

or tutors must be notified if the care requires an hospital stay of more than 12 hours.[82] Civil Law's approach to – minors aged 14 and over – is particular in that it allows them to consent to care required by their state of health but not to refuse it if their life or integrity is threatened.[83] In such cases, the consent of the person having parental authority or the tutor is sufficient. The authorization of the court must be sought when the person having surrogate decision-making authority also refuses consent to care required by the state of health of the minor.[84] Decisions made on behalf of a minor must be made in the sole interest of the minor, taking into account the minor's wishes if possible.[85]

This brief incursion into qualified minority serves to illustrate two points, one of which will be carried into the analysis of ethical decision-making in the NICU: first, children are not presumed incapable to make all health care decisions and may be allowed to exercise their burgeoning capacity in the context of these decisions; second, and more importantly, sick children's profound interest in medical decisions makes surrogate decision-making a second-best option to the full exercise of decisional autonomy. Accordingly, if newborns cannot exercise any decisional autonomy and if decision-making capacity in neonatology is always exercised on behalf of the patient, it remains that a newborn's interest should not be assimilated to her surrogate's.[86]

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[82] S. 14(2) *C.C.Q.*

[83] S. 16(2) *C.C.Q.*

[84] S. 16 *C.C.Q.*

[85] S. 12 *C.C.Q.*

[86] This approach is discussed by the Supreme Court in *E. (Mrs.) v. Eve*, [1986] 2 S.C.R. 388. As a standard for surrogate decision-making, the assimilation of the child's interests to those of her surrogates is known as "identity of interest." Ruth Macklin, "Deciding for others" in Baylis *et al.* eds, *Health Care Ethics in Canada* (Toronto: Harcourt Brace, 1995) 282 at 288-289. Arguments for identity of interest often separate along the lines of the limited or relative personhood of the newborn and the interest of the family who will have to bear the burden of caring for a disabled child, see Anspach, *supra* note 69 at 28-32; see also Earl E. Shelp, *Born to Die? Deciding the Fate of Critically Ill Newborns* (New York: The Free Press, 1986) generally (giving wide latitude to parents in life-and-death decisions by extending the ethical principle of

Best interest of the child

In Canada, jurisprudence and statutory provincial law presume parents' interest in their children's well-being and recognize them as substitute decision-makers for incapable minors.[87] If this presumption can be read as emphasizing parental interest over children's well-being, for instance by suggesting that it is in parents' interest to have healthy children, it should be made clear that children's well-being is paramount and that parental interest is only relevant insofar as it corresponds to the interest of the child. While presuming parents' privileged ability to make medical decisions on behalf of their child, Canadian law nonetheless frames surrogate decision-making within the boundaries of the best interest doctrine.

The best interest doctrine seeks to guide surrogate decision-makers as they make treatment decisions on behalf of others. [88] Where best interest guidelines are not followed, the doctrine provides a basis for judicial intervention into the decision-making process by opening the door to the state's *parens patriae* powers.[89] However, it should be

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beneficence to a newborn's immediate family); Rebecca Dresser, "Standard for Family Decision: Replacing Best Interest with Harm Prevention" (2003) 3(2) American Journal of Bioethics 54-55 (arguing for an identity of interest standard unless "clear harm" will befall the child). An interesting recap of the medical and social contexts of decisional authority in the NICU can be found in Shelp (above in this note) at 88-106.

[87] Gilmour, *supra* note 76 at 207.

[88] *Ibid.* at 225. Examples of "best interest" legislation can be found at art. 33 C.C.Q. (Every decision concerning a child shall be taken in light of the child's interests and the respect of his rights); Ontario's *Health Care Consent Act,1996,* S.O. 1996, c. 2, s. 21(2) (items to consider to determine best interest). See also *Eve v. E. (Mrs.), supra* note 85 at para. 82 (the courts' *parens patriae* jusrisdiction must be exercised in the "best interest" of the incapable person and must avoid being misled by motives and emotions). For a summary of the best interest doctrine and its application to "imperiled newborns," see Thierry Hurlimann, *'Imperiled Newborns': A Duty to Treat? From Personhood to Best Interests* (Montreal: Themis, 2005).

[89] *Parens Patriae* jurisdiction allows the state to make decisions for the protection of those who cannot care for themselves (*Eve v. E. (Mrs.) supra* note 85 at para. 73.) It effectively overrides a parent's right to make decisions on behalf of her child (*Winnipeg Child and Family Services (Northwest Area) v. G. (D.F.*), [1997] 3 S.C.R. 925 at para. 73; *B. (R.) v. Children's Aid Society of Metropolitan Toronto,*[1995] 1 S.C.R. 315)

noted that Canadian law gives parents significant freedom in discharging their parental duties by recognizing their interest in the nurturing and caring of their children as a protected liberty interest under s. 7 of the *Charter*.[90]

Parental rights and the liberty interest under s.7 **Charter**

Daily family life sees parents make a myriad of decisions on behalf of their children that may be contrary to their children's wishes or rights abstractly considered.[91] Parents are expected to temper their children's exercise of some rights as they develop the ability to manage correlating duties.[92] In a similar manner, parents' right to nurture and raise their children without state interference entails the correlating duty to preserve the interest of their children.[93] Consequently, only parental behavior that falls below a certain threshold of social acceptability and sound public policy will justify suspending the presumption that parents are in a better position than the state to determine what constitutes their child's best interest. This threshold was crossed in *B.(R.)* where parental refusal of a blood transfusion for their premature infant daughter endangered her life. However, in *Saskatchewan (Minister of Social Services) v. P.(F.)* the parents' decision to

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[*B.(R.)*]. A good – albeit outdated - review of the state's *parens patriae* jurisdiction in Canada can be found in Joseph E. Magnet & Eike-Henner W. Kluge, *Withholding Treatment from Defective Newborn Children* (Cowansville: Brown Legal Publications, 1985) at 71.

[90] Gilmour, *supra* note 76 at 225; *B.(R.), supra* note 88 ; For a thorough analysis of parents' liberty interest in the care and nurturing of their children under s. 7 of the *Charter*, see Nicholas Bala & Douglas J. Redfearn, "Family Law and the "liberty interest": Section 7 of the Canadian Charter of Rights" (1983) 15 Ottawa L. Rev. 274.

[91] *B.(R.) supra* note 88 at 373.

[92] Just as the state withholds the right to vote until one is old enough to understand politics or the right to buy alcohol until one is old enough to understand measure, parents may withhold the right to cross the street unaccompanied until one is old enough to look both ways.

[93] *B.(R.) supra* note 88 at 372. See also *Canadian Foundation for Children, Youth and the Law v. Canada (Attorney General),* [2004] 1 S.C.R. 76, 2004 SCC 4 on the balance between parental authority and children's best interest.

withhold a life-saving liver transplant for their infant son was upheld.[94] The argument in *B.(R.)* involved the parents' freedom of religion under s. 2(a) and liberty interest under s.7 of the *Charter* whereas the argument in *Saskatchewan (Minister of Social Services)* was won over the bounds of current medical practice even though the parents' refusal was initiated by their spiritual convictions as First Nations people. While the best interest doctrine instructs surrogate decision-makers and judges to consider a range of factors from medical advisability to moral interest and family environment, it seems that the latter considerations are subservient to medical indications, particularly if withholding treatment endangers the child's life.[95]

Crossing the line

The conflicts that opposed parents and healthcare workers in *B.(R.)* and *P.(F.)* first arose at the bedside of sick infants and inched their way through the Canadian court system. It must be remembered therefore that challenges to surrogate decision-making first occur at an intimate level between parents and medical caregivers and occur in the context of a genuine disagreement over what constitutes the best interest of a child. Conflicting notions of best interest are rooted in normative influences such as education, faith, life experience and expectations and the outcome of a conflict of values will either

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[94] (1990), 69 D.L.R. (4th) 134 (Sask. Prov. Ct.). See Gilmour *supra* note 76 at 229. See also Lesley Paulette, "A Choice for Ka'ila" (1993) 9 Humane Med. 13 (the author is the mother of the infant in question) and Jocelyn Downie, "'A Choice for Ka'ila:' Child Protextion and First Nations Children," (1994) 2 Health L.J. 99.

[95] Examples of highly publicized cases where parents failed to meet a minimal threshold of social acceptability can be found in Macklin *supra* note 85 at 284, in which the author reports the cases of Chad Green (Parents flying to Mexico with leukemia-stricken child against court order to resume chemotherapy. Child consequently died.), and Philip Becker (parents refusing consent to heart surgery for their mentally retarded child who had been living in a group home since birth and whom they visited only infrequently). Other examples of judicial decisions endorsing a medical definition of best interest can be found in *Re Dueck*, 171 D.L.R. (4th) 761 and *Protection de la jeunesse – 884*, [1998] R.J.Q. 816 (C.S.).

confirm or deny the legitimacy of a definition of best interest. The dynamic of decision-making confirming or denying normative positions is paralleled by the judiciary process when courts are called to arbitrate a best interest dispute.

Concluding remarks on surrogate decision-making

Canadian law offers a clear theoretical delineation of surrogate decision making affecting children and presents a step-by-step evolution through the determination of capacity, the identification of a surrogate decision-maker and the description of the basis on which decisions should be made. The reflective equilibrium between parents' role as surrogate decision-makers and the best interest doctrine reveals the legally pluralist underpinnings of formal law. By placing parents in a privileged position to determine what is the best interest of their child, Canadian law acknowledges that notions of best interest will vary in function of the normative make-up of individual families. In the next section, I will argue that the shared decision-making model advocated by the Canadian Pediatric Society modifies the pluralist interactions between parents and formal law by adding physician-based normativity to the equation. Shared decision-making introduces a twist on surrogate decision-making that recognizes the multiplicity of stakeholders involved in pediatric treatment decisions.

2.2 The turn to shared decision-making

Interdependence

Before being able to participate in treatment decisions, parents of children in the NICU must assimilate an appreciable amount of medical information about their infant's condition. The predominance placed by medical practice guidelines and Canadian courts on medical determinants of best interest demands a firm grip on "disease, its likely course, the treatment options, the possibility to choose no treatment, the benefits and risks for each option and the likely outcomes, such as length of hospitalization or recovery, scars, and so on."[96] Competing interests, especially family issues or religious beliefs, are considered "important," but are nonetheless denied determining influence beyond what a "reasonable person of goodwill" would decide in a similar situation.[97] The reliance of the medico-legal establishment on medical determinants of best interest puts families and physicians in a situation of inter-dependence when faced with a critically ill infant: parents depend on medical staff – physicians, nurses, chaplains, social workers – to make informed decisions, and health care professionals depend on parents to make effective decisions in the best interest of their child. This interdependence is at the root of the shared decision-making model adopted by the Canadian Paediatric Society and used throughout Canadian NICUs.

A picture of the bedside through a CPS lens

The Canadian Paediatric Society's statement on treatment decisions regarding infants, children and adolescents starts by recognizing the intrinsic dignity and value of

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[96] CPS Statement *supra* note 62 at 100.

[97] *Ibid.* It is interesting to note that in *Saskatchewan (Ministry of Social Services) supra* note 93; *R.(B.) supra* note 88 ; *Re Dueck* and *Protection de la jeunesse – 884, supra* note 94, firm religious convictions and the impact of coerced treatment on these convictions were not even considered in the determination of best interest. In fact, both decisions consider unwavering faith in God's healing power as a sign of immaturity justifying overriding the minor's decision to refuse treatment. In *R.(B.)*, the parents'religious convictions are examined in light of their *Charter* guaranteed freedom of religion and their liberty interest under s. 7. In *Saskatchewan (Ministry of Social Services)* the parents' religious convictions were ignored once it was established that refusing a liver transplant fell within the boundaries of current medical practice. In *Re Dueck* and *Protection de la jeunesse- 884*, both concerning mature minors with firm religious convictions, the minors' unwavering faith in God's healing powers was used to demonstrate their inability to appreciate relevant medical information and their decisional incapacity.

all children, regardless of age, capacity and physical or mental ability.[98] The CPS' guiding principles assume that children should become principal decision-makers for themselves as soon as they have the capacity to take part in the decision-making process.[99] However, the purpose of the statement is to offer principles and strategies to physicians and surrogate decision-makers for incapable minors. The CPS reviews the basic principles of informed consent – information, capacity and voluntariness – before examining the tenets of surrogate capacity and best interest.[100]

For the purpose of this thesis on legal pluralism and decision-making in the NICU, two features of the CPS Statement will be highlighted: the relevance of non-medical factors in the decision-making process and the definition of best interest.

Family issues: non-medical factors in the decision-making process

The CPS' first acknowledgement of what it terms "family issues" occurs in its declaration of principles by affirming their importance and relevance. However, if family issues must be "considered" they give right of way to the patient's best interest which is the health professional's primary concern.[101] Family issues are again mentioned in the CPS review of the general principles of informed consent where decisions are seen as "a

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[98] The CPS is a voluntary professional organization representing more than 2,500 pediatricians, pediatric subspecialists, pediatric residents, and other people who work with and care for children. It is governed by an elected Board of Directors and is committed to advocacy, education and research in pediatrics. Its position statements and clinical practice guidelines are published in peer-reviewed journals but are not legally binding. They do however have a normative effect on the practice of Canadian pediatricians. See online: Canadian Pediatric Society <http://www.cps.ca/English/insidecps/aboutcps.htm> [accessed November 14, 2007].

[99] For more on involving children in medical decisions, see Christine Harrison *et al.* "Bioethics for clinicians: 9. Involving children in medical decisions" (1997) 156 (6)Can Med Assoc J 825.

[100] CPA Statement "Decisions regarding infants, children and adolescents" *supra* note 62 at 99-100.

[101] *Ibid.* at 99.

combination of known facts and personal values."[102] But personal values cannot be meaningfully expressed in the absence of adequate and appropriate information. Seen as the nexus of surrogate decision-making and the determination of a patient's best interest, medical information is central to decision-making for incapable minors. In that view, best interest is determined by carefully considering a child's chances of survival, the harms and benefits of a treatment, long- and short-term *medical* outcomes and long-term quality-of-life implications.[103] Again, "values, preferences, beliefs and expectations of the family" are mentioned as "important" but while they "should not be ignored" and be "addressed sensitively" they can sometimes conflict with the child's best interest and affect the family's ability to make decisions on behalf of their child.[104] Competing interests can directly affect a child's best interest in which case, balancing competing interests must be achieved through a standard of 'reasonableness.'[105] The CPS instructs its members to accept parental decisions contrary to theirs "unless it is obvious to many that the decision is patently not in the best interest of the child or adolescent."[106] In such cases, pediatricians should seek a second opinion and enlist the assistance of an ethics committee or consultant before initiating child protection procedures.[107]

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[102] *Ibid.*

[103] *Ibid.* at 100.

[104] *Ibid.*

[105] In Lainie Friedman Ross, *Children, Families and Health Care Decision-Making* (Oxford: Clarendon Press, 1998), the author questions the relevance of the sole interest of the child's doctrine for liberal societies. Giving the example of Amy, a 9-year-old child who suffers from cerebral palsy, Friedman Ross explains that Amy could get better rehabilitation in a large urban setting. However, moving from their rural setting would cause severe financial hardship and affect Amy's well-being consequently. Amy's family can opt for sub-optimal medical care for Amy only if the move will cause her greater hardship. They cannot however elect to stay on their farm if the move will impede their rights and aspirations. Friedman Ross concludes: "… their parental duties trump their parental rights." At 21.

[106] CPS Statement *supra* note 62 at 102.

[107] *Ibid.* at 102-103.

Defining best interest: who does it and how?

If the CPS acknowledges the privileged role of parents in the determination of a child's best interest and the possibility to consider extra-medical factors when making such determination, it is only in cases of medical uncertainty or medical neutrality. Extraneous considerations cannot outweigh physical well-being and no forethought is given to the possibility of returning a physically healthy child into a culturally – religiously, spiritually etc. – scarred family.[108] The possibility that non-medical normative influences rooted in a family's background may be an expression of deep care and concern is overlooked by an adversarial system that pits *those-who-care* against *those-who-don't*. Yet, the same factors, recast in terms of internormativity, may exert a stronger normative influence on the behavior and priorities of a child's proxies than medical norms of best interest.

The CPS statement does not acknowledge that health care professionals may be subjected to "values, preferences, beliefs and expectations." The role of health professionals is to impart adequate medical information. When the child's best interest is unclear – which may occur because of insufficient information but also in the context of an ethical conflict – the presumption should be in favor of life-saving or life-sustaining treatment.[109] This presumption in and of itself effectively evacuates many ethical conflicts and places parents clearly on the outskirts of the medical decision-making process. Still,

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[108] On this topic, if the reader finds it difficult to appreciate the reality and magnitude of such scarring, I strongly recommend reading Anne Fadiman, *The Spirit Catches You and You Fall Down: A Hmong Child, Her American Doctors and the Collision of Two Cultures* (New York: Farrar, Strauss and Giroux, 1997). Fadiman offers a well-balanced and heartfelt chronicle of Lia Lee's medical course. Lia was the youngest child of a large immigrant Hmong family in Merced, California. She suffered from severe epileptic seizures, which was seen as a gift in her parents' culture but as a curse in California's technologically advanced society.

[109] CPS Statement, *supra* note 62 at 100.

the CPS recognizes that genuine conflicts of values may place a child's parents and treating team at odds. In such cases, parental authority is to be respected "unless it is obvious to many that the decision is patently not in the best interest of the child…"[110] Moreover, parental authority should be "critically scrutinized" when disagreement occurs over "medical facts" such as prognosis, risks and benefits.[111] When disagreement persists, the CPS encourages its members to seek a second opinion, enlist the help of an institutional ethics committee or consultant and, if all else fails, initiate child protection procedures.[112]

A critique of the CPS statement

A critical reading of the CPS statement highlights several issues of relevance for a pluralist critique of ethical decision-making in the NICU. First, the emphasis on the medical determination of best interest ensures that the emergence of ethical dilemmas will occur in areas that are more familiar to the healthcare team than to the parents. Certainty over the medical best interest of a child eliminates the possibility of an ethical dilemma insofar as the family is not given the opportunity to partake in uncontested medical decisions. Parental uneasiness with medical facts is to be met with "critical scrutiny" and considered as an inability to make a best interest decision.[113] Secondly, by emphasizing "family issues" without recognizing the existence of "health care issues" – including the experience and beliefs of individual health care workers – the CPS encourages a dichotomy of values where parental concerns are negatively labeled as "issues" whereas

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[110] *Ibid.* at 102.

[111] *Ibid.*

[112] *Ibid.*

[113] *Ibid.*

health care workers values and experiences are integrated to the "information" label.[114] When ethical conflicts arise between parents and health care workers over the definition of a child's best interest, parents face an uphill battle where their "issues" are compared to "medical information."

Nowhere does the CPS statement suggest that best interest could be defined differently than by bio-medical standards. Accordingly, the social space where parents and health care workers meet to make shared decisions on behalf of sick children is dominated by medical normative influences. What are the implications of this model of shared decision-making for the organization of relationships – and the emergence of law, broadly defined – in the NICU? With the CPS Statement as a starting point, I will take a closer look at the reality of shared decision-making in Canadian NICU and the influence of parents in the determination of the best interest standard.

2.3 How shared is shared? The accommodation of shared decision-making in the NICU

A hypothesis

In the previous section, I argued that Canadian medical practice guidelines emphasize a strict definition of best interest informed by biomedical norms and that doing

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[114] The relevance of "labeling" in health care delivery has been highlighted in Carol A. Heimer & Lisa R. Staffen, "Interdependence and reintegrative social control: Labeling and reforming 'inappropriate' parents in neonatal intensive care units" in Michael Freeman, ed., *Children, Medicine and the Law* (Burlington: Ashgate Publishing, 2005) at 283. See also Jeanne Harley Guillemin & Lynda Lytle Holmstrom, *Mixed Blessings: Intensive Care for Newborns* (New York: Oxford University Press, 1986) at 196-197 on labeling as a tool of professional control. Labeling and categorizing interactions and situations is also an important function of law, see R. A. MacDonald, *Lessons of Everyday, supra* note 73 at 115.

so effectively mutes parental voices that might offer a different, albeit important, perspective. The inclusion of parental voices, conceived as the expression of family-based normativity, is assumed by Canadian surrogate decision-making principles but the normative influence of the CPS principles on health care professionals causes them to effectively deny parental input at the child's bedside. In the present section, I will develop a hypothesis based on the predominance of the medical norm and inspired by research on parental involvement in NICU.[115]

I will argue that effective *shared* decision-making only occurs in cases of medical uncertainty or neutrality. When treatment decisions are medically uncontested, that is, when health care professionals are certain that a treatment is in the best interest of an infant, parents are not given the opportunity to oppose or challenge the treatment decision with a competing definition of best interest. When the best interest of the patient has already been ascertained by medical norms, as is the case when a blood transfusion is ordered for the child of Jehovah's Witness parents, the medical norm of success trumps the parents' definition of best interest as including religion-based normativity.[116] The "shared" component of decision-making occurs only in the context of decisions that have been identified by health care professionals as holding an element of uncertainty that should be arbitrated by the infants' parents. This decision-making dynamic is problematic

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[115] This hypothesis is an integral part of Pinch *supra* note 1, Renée R. Anspach, *supra* note 69, and Kristina Orfali, "Parental Role in Medical Decision-Making: Fact or Fiction? A Comparative Study of Ethical Dilemmas in French and American Neonatal Intensive Care Units" (2004) 58 Social Science & Medicine 2009-2022.

[116] The purpose of this statement is to illustrate a decision-making dynamic, not to argue in favor of denying blood transfusions to critically ill infants or to pick on Jehovah's Witnesses. However, Jehovah's Witnesses refusal of blood transfusions are known to grab media attention and therefore constitutes an easy example.

in that it puts health care professionals in control of a process that should be shared between equals.

Decisions as social acts: Renée R. Anspach's contribution

The decision-making dynamics highlighted in the previous paragraph shows how formal law is concurrently contributing to and transformed by human interactions. This emphasis on human interactions as law-creating and law-abiding falls in line with the themes of Renée R. Anspach's sociological study of life-and-death decisions in the NICU as well as with the Fuller-inspired pluralist critique presented in my previous chapter.[117] By emphasizing the collective nature of the decision-making process, Anspach warns against the tendency to locate the source of decision-making problems with the individual – whether staff member, parent or patient – and demonstrates how sociology can lead to a better understanding of moral and ethical choices.[118] Because sociology is not wrapped around the axiom of autonomy, unlike law and bioethics, Anspach's analysis of decision-making in the NICU reveals the processes by which decisions are reached and the social structure where they are located.[119] According to Anspach, if parents find themselves left out of the decision-making process, it has much more to do with the socio-legal organization of the NICU – understood broadly as including public policy issues such as

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[117] Anspach's study, *supra* note 69, will be used throughout my thesis for insight into the daily interactions taking place in the NICU.

[118] Anspach, *ibid.* at 20.

[119] *Ibid.* at 20-22. For examples of bioethical literature questioning the hegemony of autonomy over other bioethical principles, see Anne Dochin, "Understanding Autonomy Relationally: Toward a Reconfiguration of Bioethical Principles" (2001) 26 J Med Philos 365-386. See also: Susan Sherwin, "A Relational Approach to Autonomy in Health Care" in Susan Sherwin, ed. *The Politics of Women's Health* (Philadelphia: Temple University Press, 1998) at 19-47 as well as Virginia A.Sharpe, "Justice and Care: The Implication of the Kohlberg-Gilligan Debate for Medical Ethics" (1992) 13 Theor Med 295-318. Relational theory has not yet played a significant role in health law and policy but research into its potential is emerging: Jocelyn Downie, "Relational Theory and Health Law and Policy" (Paper presented to the National Health Law Conference, Banff, 09 November 2007) [Unpublished].

resource allocation and professional liability – than with the individuals present at the bedside.[120]

If a sociological perspective can be the source of important insight for a pluralist critique of legal interactions in the NICU, it also presents some important limitations. We saw while reviewing scholarship on legal pluralism that circumscribing an area of study to a particular social field tended to limit the type of interactions considered "legal" or "law-creating" to those which can be observed within that field to the exclusion of others.[121] If sociology covers a wider normative landscape by looking at legal interactions with a telescope, legal pluralism demands that legal interactions be inspected with a magnifying glass to reveal how legal subjects maneuver their normative landscape and how the creation of law occurs through this maneuvering. A clear depiction of interactions in the NICU also requires a close examination of its everyday life.

Understanding the NICU: The importance of everyday life

Putting decision-making in the NICU under the spotlight risks revealing some of its blemishes, but it also highlights the shortcomings of the formal and informal processes whereby decisions are made. Putting law in the context of everyday life allows us to look at the sometimes unanticipated way in which people – individually or socially – respond, ignore or re-create law.[122] The pluralist critique of law posits law's dependence on everyday life to define its scope, for instance by giving meaning to legal concepts such as

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[120] Anspach *ibid.* at 22. See also Pinch, *supra* note 1 at 35.

[121] Above p. 23-24 (chapter 1).

[122] Austin Sarat & Thomas R. Kearns, "Beyond the Great Divide: Forms of Legal Scholarship and Everyday Life" in Sarat & Kearns *supra* note 58 at 21.

"reasonable," "excessive" or "appropriate."[123] However, if law is dependant on everyday life, it also defines everyday life by classifying the acceptability of certain behaviors patterns, the preservation or transformation of certain values and the validation of certain experiences or beliefs.[124]

Seeing law as simultaneously creating and created through everyday interactions, we can see how the law of surrogate decision-making acts to recognize and synthesize important Canadian values such as physical integrity, informed choice, the importance of the family as fundamental building block of society, and children's need for protection. In a similar manner, clinical practice guidelines on shared decision-making affect bedside behavior by imposing a recognition of physicians' duty of care and their obligation to discharge this duty by dispensing the best medical care possible.[125] However, the law of surrogate decision-making is also defined by everyday life in the high-strung environment of the NICU. Law-creating interactions emerge when health care professionals accommodate surrogate decision-making to neonatal intensive care. The "everyday life perspective" bridges the gap between the relatively removed environment of policy-making and that of immediate medical decision-making.[126]

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[123] David M. Engels, "Law in the Domains of Everyday Life: The Construction of Community and Difference," in Sarat & Kearns, *supra* note 58 at 125. See also Clifford Geertz, *Local Knowledge: Fact and Law in Comparative Perspective* (Basic Books, 1983) at 175, describing law as a "distinctive manner of imagining the real," Geertz assimilates the phenomenon of factual representation to "the rendering of fact so that lawyers can plead it, judges can hear it, and juries can settle it …" See also R.A. MacDonald "Lessons of Everyday law" *supra* note 73 on the characterization of situation as a key element of legal analysis.

[124] Engels, *ibid.* at 124.

[125] *Crits v. Sylvester* [1956] O.R. 132, aff'd [1973] 5CR. 220 (Sup Ct Can) at 143 describes standard of care as "the degree of care and skill which would reasonably be expected of a normal, prudent practitioner of the same experience and standing."

[126] Engels, *supra* note 123 at 124.

2.4 Concluding Remarks

Canadian law and medical practice guidelines combine to create a clear hierarchy of surrogate decision-making authority while recognizing the imbalance of medical knowledge and experience between parents and health care professionals. However, the emphasis placed on the bio-medical definition of a child's best interests creates a gap between the role given to parents by law and parents' ability to exercise this role independently. This gap between formal law and "everyday life" provides a fertile environment for the emergence of normative orders – or plural law – meant to palliate law's inability to address the subtleties of the medical encounter at the child's bedside.

In and of itself, law's limited purview in matters of pediatric surrogate decision-making does not explain how or why normative interactions arise in NICU. The next chapter will review some significant contributions to empirical research in the NICU to reflect on distinguishing features of neonatal care wielding an impact on the expression of legal pluralism. If formal law and medical guidelines open the door to parental involvement only in cases of medical uncertainty or neutrality, a study of the construction of ethical dilemmas in the NICU will reveal how parents and health care professionals engage in the decision-making process when a baby's prognosis is medically uncertain.

Chapter 3: Ethical dilemmas in the NICU

To gain better understanding of the decision-making dynamics in the NICU we must first look at the emergence of treatment dilemmas surrounding the care of imperiled newborns. Knowing the scope and magnitude of these dilemmas yields a clearer picture of the normative environment in which they arise, as well as a sense of the emotional turmoil and urgency that characterizes them.

The purpose of this chapter is twofold. First, it seeks to further the analysis of critical legal pluralism in the NICU by drawing attention to features of the neonatal context that foster the emergence of plural law. Critical legal pluralism posits that the structures of law and legal subjectivity are created by the subjects rather than determined by social factors. Features of neonatal critical care such as prenatal decisions to withhold or provide life-saving treatment, prognostic uncertainty and withdrawal of life-sustaining treatment will be illustrated using examples of parental experiences drawn from empirical research. From these examples of lived experiences, legally pluralist behaviors will be highlighted and analyzed. Second, it seeks to describe the challenges that arise when multiple perspectives of a dilemma enter into contact. Doing so, chapter 3 lays the foundations for chapter 4 which will draw a comparative analysis between the role given to parents by formal law and the normative role they are in fact given at their infant's bedside. In this chapter, I argue that the prognostic uncertainty characteristic of neonatal intensive care gives most treatment decisions in the NICU an element of ethical uncertainty that cannot be meaningfully arbitrated by formal legal rules of best interest and surrogate decision-making. In this context, legal pluralism occurs when decision-makers respond to the inadequacy of formal rules by adapting and recreating them.

3.1 Forks in the road: Ethical dilemmas in the NICU

In neonatal intensive care, many treatment decisions have ethical implications. The difficulty of predicting neonatal outcomes -- that is to predict which children will benefit from invasive life-saving procedures and which children will develop serious health complications as a result of the same procedures -- means that decision-makers often weigh treatment options in light of their personal moral orientation[127] or what John Lantos calls the "individual instincts of conscience."[128] To analyze decision-making in the NICU, I will use an archetypical case of premature labor and delivery and retell the story in terms of the issues it raised and the decisions it triggered. The archetypical case I will use is representative of a typical course of treatment[129] in NICU for a child with respiratory complications due to extreme prematurity.[130]

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[127] Moral orientation is the psychological dimension of decision-making involving ethical dilemmas. Whereas bioethics focuses of the philosophical examination of ethical issues, moral orientation describes individual values, beliefs and traditions brought to the decision-making process by stakeholders, see Pinch, *supra* note 1 at 177.

[128] John D. Lantos, *The Lazarus Case: Life-and-Death Issues in Neonatal Intensive Care* (Baltimore: Johns Hopkins University Press, 2001).

[129] My sense of what constitutes a "typical course of treatment" in the NICU is a compendium of practical experience gained through two ethics placements in neonatal intensive care – one at the Montreal Children's Hospital in Montreal in the winter of 2007 and one at the Children Hospital of Eastern Ontario in the summer and fall of the same year – and the general research done for the purpose of this thesis.

[130] Extreme prematurity is the lower rung on a descriptive scale of prematurity. Because the risk of complications related to prematurity grows as gestational age decreases, premature infants are often classified in the bioethical literature according to gestational age. However, this classification can be misleading in light of the high rate of inaccuracy of dating pregnancy using the date of the mother's last menstruations or ultrasound imaging, see Fetus and Newborn Committee, Canadian Paediatric Society & Maternal-Fetal Medicine Committee, Society of Obstetricians and Gynaecologists of Canada, "Management of the woman with threatened birth of an infant of extremely low gestational age" (1994) 151 (5) Can Med Assoc J 547 at 548 [CPS/SOGC Guidelines] (guidelines currently under revision). Since the World Health Organization International Classification of Disease 10th revision (ICD-10) instructs health

In this section, ethical dilemmas will be identified without using any particular ethical theory as a yardstick. The goal of this section is not to discuss what is ethically problematic in light of a theoretical framework but to identify ethical gray zones as reported in the medical, legal and bioethical literature, particularly as they affect parents of NICU patients. Secondly, this section will not launch into a discussion of the genesis of these ethical gray zones since such discussion would take us beyond the scope of this thesis into the history and science of neonatal medicine.[131]

Kate's Story: A Window to the NICU

Admissions to NICU generally fall into three categories: full term or near term babies with acute illnesses, babies with congenital anomalies and babies born prematurely.[132] Each category of patients is affected by characteristic ethical quandaries. For instance, term babies with acute illnesses are usually the least morally controversial given that their conditions are usually treatable and transient, but ethical dilemmas arise

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care providers to give priority assignment to birth weight when describing disorders related to short gestation, a consistent definition of extreme prematurity is difficult to come by, online WHO <http://www.who.int/classifications/apps/icd/icd10online/> [Accessed November 17, 2007]. Often, extreme prematurity describes a birth occurring before 28 completed weeks of gestation out of an average of 37 to 42, Geoffrey Miller, *Extreme Prematurity: Practices, Bioethics and the Law* (New York: Cambridge University Press, 2007) at 7 and Pauline Challinor Mifflin, *Saving Very Premature Babies: Key Ethical Issues* (London: Elsevier Science, 2003) at 13; however, the CPS/SOGC Guidelines describe extreme prematurity as occurring between 22 and 26 completed weeks of gestation, CPS/SOGC Guidelines at 548. If birth weight, unlike gestational age, can be accurately determined, it is unfortunately unavailable to neonatologists and obstetricians before birth. Medical management of a woman threatening to deliver an extremely premature infant must be made according to estimated gestational age, CPS/SOGC Guidelines at 549.

[131] Readers interested in the history and science of neonatology are invited to read John D. Lantos & William L. Meadow, *Neonatal Bioethics : The Moral Challenges of Medical Innovation* (Baltimore : Johns Hopkins University Press, 2006), or John D. Lantos, *The Lazarus Case, supra* note 128.

[132] See Lantos & Meadow, *supra* note 131 at 14. I believe Lantos & Meadow's list somewhat incomplete as it does not include previously healthy fetuses who present an hypoxic-ischemic injury to the brain (or other organs) following perinatal asphysia. Such children are not congenitally malformed, nor is their condition always transient or treatable, yet they may suffer significant neurologic impairment and be affected by prognosis uncertainty.

when the recommended treatment is partially successful or experimental. Babies with congenital anomalies raise ethical concerns about anticipated quality of life and the purpose of treating the symptoms of an untreatable underlying condition.[133] However, prematurity lends itself particularly well to the general study of ethical dilemmas in the NICU for two reasons. First, it is the most important cause of perinatal mortality and morbidity in industrialized countries, making premature infants representative of the demographic composition of the NICU. [134] Secondly, ethical dilemmas emerging from prematurity include the moral considerations found in the other two categories of infants plus a new one: long term prognostic uncertainty.[135] While we know that children born prematurely are at risk of impairment and disability, it is impossible to predict long term outcomes before birth and often for several weeks afterwards.[136] The range of prognoses for prematurity related conditions covers "a spectrum of outcomes, from very best to very worst"[137] but treatment must be initiated before the child's long term prognosis can be ascertained. Prognostic uncertainty adds a new dimension to ethical reflection by requiring that the risks of treating infants who will be severely damaged by the circumstances of their birth be balanced against the risks of not treating children who would otherwise have lead, healthy, happy, lives. This is the tale of one infant:

> Kate was born at 25 weeks gestation, by ceasarean, weighing 750 grams (1 lb 11oz). … During the first 24 hours she suffered breathing problems and

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[133] *Ibid.* at 14-17.
[134] Preterm birth accounts for 60% to 80% of deaths of infants without congenital anomalies and 32.8% of all neonatal deaths. Neonatal mortality is defined as mortality occurring in the first 28 days of life. Mortality between the 28th day of life and 1 year is defined as infant mortality. Health Canada. *Canadian Perinatal Health Report, 2003* (Ottawa: Minister of Public Works and Government Services Canada, 2003) figure 4.16 at 92.
[135] Lantos & Meadow, *supra* note 131 at 15-16.
[136] CPS/SOGC Guidelines, *supra* note 130 at 549.
[137] *Ibid.*

> needed to be resuscitated; these continued over the next few days in addition to which she suffered internal bleeding and needed a transfusion. She underwent physiotherapy on her tiny chest and tolerated a feed of ½ ml breast milk every two hours via a nasogastric tube.
>
> On the tenth day, she suffered yet another setback. She developed a chest infection so antibiotics were prescribed and she was put back onto the ventilator. During the next few days, she had several episodes when she stopped breathing and had to be resuscitated.
>
> When Kate was nearly three weeks old, her parents were informed that she was to be transferred to a specialist children's hospital to undergo surgery for a hole in the heart as soon as a bed became available, At this point, she was tolerating 5mls of breast milk every hour. … She was operated on at just three weeks old and returned to her original hospital later the same day, still on the ventilator and sedated with morphine. Two days later, the morphine was discontinued and Kate began her feeding regime once more.
>
> One week later, she was reported to be doing well off the ventilator and on the CPAP (continuous positive airway pressure) machine. She was taking 7mls of milk every hour and had been out of the incubator for a cuddle with Mum.
>
> At 5 weeks (30 weeks gestational age) she weighed 1100 grams (2lb 9oz) and could be taken off the CPAP for short spells. The CPAP applies air pressure to keep her tiny lungs expanded, via an endotracheal tube or via the nose. Her parents were delighted with her progress and were able to nurse her regularly on their visits to the special care unit.
>
> Kate came out of intensive care after 8 weeks and was transferred to the high dependency unit, weighing 1650 grams (3lb 10oz). She was being fed every 3 hours with 40 mls milk and when sucking became too much for her, the nasogastric tube was reintroduced. At this point, she could manage some short spells of breathing without the CPAP machine.
>
> At the age of 13 weeks, and weighing 2500 grams (5 ½ lbs), she was discharged from hospital into the care of her parents. Kate is still too young for any potential learning disabilities to be assessed accurately. All the signs so far are encouraging … [138]

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[138] Taken from Mifflin *supra* note 130 at 29-30.

To treat or not to treat: Ethical reflection at the beginning of life

Treatment decisions concerning children of extremely low birth weight might arise before their birth.[139] The onset of premature labor or the suspicion of premature delivery triggers a progression of bioethical reflection starting with an exploration of available treatments,[140] which available treatments are adequate for the patient and whether or not adequate treatments should be initiated.[141] In Kate's case, the first ethical dilemma emerged when deciding to perform a cesarean section to deliver an extremely low birth weight (ELBW) infant. Cesarean delivery carries more risk to the mother than vaginal delivery but is believed to allow quicker access to the newborn.[142] The decision to perform a cesarean section to deliver a child at the margins of viability has medical implications for the mother – who will face increased morbidity risks for this as well as future pregnancies – and for her child whose chances of survival may be optimized by immediate surgical delivery.[143]

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[139] The World Health Organization classifies birth weight as follows: extremely low birth weight (ELBW) 999 grams or less, other low birth weight between 1000 and 2499 grams. Other weight categories found in the literature are: low birth weight (LBW) <2500 grams, very low birth weight <1500 grams, ELBW <1000 grams and micropreemies 500-600 grams. Pinch, *supra* note 1 at 276, see also Tom Lissauer & Avroy Fanaroff, *Neonatology at a Glance* (Oxford: Blackwell Publishing, 2006) at "2 Epidemiology."

[140] In Canada, the regionalization of neonatal/perinatal care allows patients to be referred to the facility with the appropriate level of care depending on their condition. The CPS classifies Canadian neonatal/perinatal care facilities according to a three-level scale. A detailed description of levels of neonatal care can be found in Canadian Pediatric Society, "CPS Statement FN 2006-02, Levels of Neonatal Care" (2006) 11(5) Paediatr Child Health at 303 [CPS Statement, "Levels of Neonatal Care"].

[141] Pinch, *supra* note 1 at 22; CPS/SOGC Guidelines, *supra* note 130 at 549;

[142] For a discussion of the ethical implications of performing cesarean sections to deliver non-viable infants, see Joseph A. Spinnato *et al.* "Aggressive Intrapartum Management of Lethal Fetal Anomalies: Beyond Fetal Beneficence" (1995) 85 (1) Obstetrics & Gynecology 89.

[143] The benefits of cesarean delivery for premature infants are debated, see M.H. Malloy, L. Onstad & E. Wright, "The Effect of Cesarean Delivery on Birth Outcome in Extremely Low Birth Weight Infants" (1991) 77 Obstetrics & Gynecology 498 (cesarean section is not associated with lower risk of mortality or severe intraventricular hemorrhage) and S.F. Bottoms *et al.* "Obstetric Determinants of Neonatal Survival: Influence of Willingness to Perform Cesarean Delivery on Survival of Extremely Low-Birth-Weight Infants" (1997) 176 (5) American Journal of Obstetrics & Gynecology 960 (willingness to perform cesarean delivery is associated with both increase in survival and intact survival above 26 weeks gestation and birth weight $\geq$ 800 grams). Canadian guidelines on the management of women with threatened birth of an ELBW infant recommend avoiding unnecessary c-sections by denying them before 22 completed weeks' gestation

Parents' ethical experiences at the onset of premature delivery can be inferred from results of empirical research in prenatal decision-making. In a study conducted in a perinatal tertiary care center in Montreal, neonatologists were found to focus on the medical management of the unborn baby – the "baby project" – while parents were still grieving their parenthood project.[144] Payot *et al.*'s observations are echoed by Winnifred Ellenchild Pinch who notes that parents of NICU patients always describe their experiences in the NICU within the "broader context of their lives."[145] For instance, Pinch's research subjects started each narrative about their child's stay in the NICU with an earlier event such as the circumstances of the infant's conception, their feelings toward the pregnancy or the identity of the individuals involved in their care.[146] When "hurled into grief and loss" by the threatened birth of a marginally viable infant, subjects in Payot *et al.* expressed guilt as they realized that they were more concerned about the loss of the "ideal family" than by the potential suffering of the infant.[147]

The normative situation of mothers considering invasive procedures and drug regimen for the benefit of their unborn infant presents an interesting case study in legal pluralism. In the Canadian legal landscape, the fetus is not legally considered a person

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and providing the newborn with compassionate care rather than active treatment, see CPS/SOGC Guidelines, *supra* note 130 at 550-551.

[144] Antoine Payot *et al.* "Deciding to resuscitate extremely premature babies: How do parents and neonatologists engage in the decision?" (2007) 64 Social Science & Medicine 1487. The study does not clearly indicate which perinatal tiertiary care centre was under study but the authors' academic affiliations are with the Université de Montréal Faculty of Medicine and with Ste-Justine Hospital in Montreal.

[145] Pinch, *supra* note 1 at 49. Pinch's longitudinal research project targeted parental perceptions of ethical decision-making in the NICU. Her data was collected over three distinct phases that began prior to the infant's discharge (phase I), pursued 6 months after discharge (phase II) and four year after discharge (phase III), *ibid.* at xiii.

[146] *Ibid.* at 50-51.

[147] *Ibid.* at 1492.

until it is born alive and viable.[148] Consequently, neonatologists engaging in the prenatal decision-making process do not technically have a patient and parents have no formal duty to make decisions in the best interest of their child.[149] However, empirical research covering the prenatal phase of neonatal critical care shows that parents engaged in the prenatal decision-making process do so with a very strong commitment to the best interest of the child and welcome the participation of neonatologists as their infant's pediatrician. Parents and neonatologists accommodate existing rules of legal personhood, therapeutic relationship and best interest by committing to a more exacting standard of fetal best interest than formal law requires of them.

Likewise, Canadian law does not allow the use of a woman's body to protect the fetus from harm.[150] It follows that women are under no legal obligation to submit to invasive physical procedures and toxic drug regimen to maximize their infant's safe delivery. However, women routinely offer the use of their bodies to the physicians trying to maximize their infant's outcome. Parental narratives in Helen Harrison's *Premature Baby Book* relate an emergency c-section performed before the mother was adequately anesthetized and a case of forceps delivery where the mother was denied anesthetics because of side effects on the infant's respiratory function.[151] One of Pinch's testimonies offers a compelling story of self-abnegation for the benefit of an unborn infant who does not yet exist in the eye of the law:

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[148] Tremblay *v.* Daigle, [1989] 2 S.C.R. 530.

[149] Payot *et al. supra* note 144 at 1497.

[150] *Winnipeg Child and Family Services (Northwest Area) v. G. (D.F.)*, *supra* note 88.

[151] Helen Harrison, *The Premature Baby Book: A Parents' Guide to Coping and Caring in the First Year* (New York: St.Martin's Press, 1983) at 40 and 26. Because Harrison's book is a guide for parents, it is not meant as an academic reference.

> "Ethyl … was placed on bed rest and given magnesium sulfate and terbutaline which averted the delivery for another four weeks. Ethyl also contracted a kidney infection. She thought she would "mentally lose it" during this time, which she attributed to the effects of the medications. Ethyl described the result of this pharmacological prevention of preterm labor as simultaneously, intensely relaxing the body while also causing another acute sensation, like a powerful urge to speed up and move. This dual sensation was accompanied by headaches and a perception that her eyes would pop out. Additionally, she had pain from the kidney infection. Ethyl finally requested some adjustment of the medication, either a lower dose or a discontinuing of one or the other medication … The magnesium sulfate was discontinued but, two hours later, the baby's heartbeat became critical and a caesarian section was performed." [152]

Despite the absence of formal legal duty to put their infant's interest before their own, mothers struggling with the additional guilt associated with a failed pregnancy often saw difficult decisions as a duty of care toward their baby:

> "She saw caring for her infant as a moral responsibility, as the child was completely dependant on her. … The baby's status was clearly more important when the decision to perform a c-section was made. Her caring for the child included any sacrifice she needed to make for the infant's health."[153]

The moral responsibility that orients parental decision-making, above and beyond the minimal requirements of formal law is a perfect example of legal pluralism in health care where parents re-draw the boundaries of law to adapt it to the needs of their situation. In this case, the inability of formal law to even reach the infant before birth causes families and physicians to create the rules governing their relationship toward the infant and each other. Prenatal decision-making also highlights the limits of law to arbitrate ethical dilemmas meaningfully in health care, emphasizing the relative weight of normative influences such as faith, experience, socio-cultural background, personal

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[152] Pinch, *supra* note 1 at 54. Ethyl's baby was born with a birth weight of 735 g. and was discharged home after a three-month residence in the NICU.

[153] *Ibid.* at 196. There is also anecdotal evidence of mothers lying about their gestational age to secure cesarean delivery and treatment for their premature infants, see "'Living Proof' Stirs Debate," News, *The National Post* (26 February 2007) A3.

expectations and values vis-à-vis parenting and emotions in deciding what *should* be done for a particular newborn.

Coming to term with uncertainty

When a woman presents signs of premature labor, she must engage immediately in life-altering ethical reflection. Coming back to Kate's case, her birth at 25 weeks' gestation may not appear as a dilemma under current neonatal resuscitation guidelines, but prognostic uncertainty at 25 weeks may remain problematic for her parents.[154] The CPS/SOGC declaration that the positive outlook of infants born after 25 weeks gestation justifies systematic life-saving treatment reflects medical norms of certitude reached after studying intact survival rates. However, outcomes of infants born at 25 weeks gestation are by no means predictable or certain.[155] Because they engage in the decision-making process from different standpoints, parents and neonatologists perceive information about the child's condition, prognosis and probable outcome differently. I posit that engaging in the decision-making process from different standpoints not only challenges the integrity of the decision-making process but equally affects perceptions of what is ethically problematic and, consequently, the norms called upon to reach the right – ethical, moral – decision.

Payot *et al.* observed that some parents come to terms with the uncertainty of outcomes related by neonatologists by reformulating risks of mortality and morbidity into the certainty of having a healthy child in order to justify the decision to provide or

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[154] CPS/SOGC Guidelines, *supra* note 130 at 551.

[155] According to the CPS/SOGC Guidelines, at 551, infants born at 25 to 26 weeks gestation have survival rates of 50% to 80% with rates of impairments and disability affecting between 10% to 25% of survivors.

withhold life-saving treatment. Other parents believe that the overemphasis put by medical staff on risks distracts them from “seeing the good side” and refuse to dwell on grim prognoses.[156] In light of the difference in perception and assimilation of information, Payot *et al.* report that parents and neonatologists describe differently the elements that constitute a “right” decision.[157] Neonatologists emphasize informed consent as the basis for a right decision, as related in this narrative from Payot *et al.:*

> “I feel comfortable in caring for a baby when I know, I feel that the parents really know and understand … they know what we need them to know. They really came to a decision with the knowledge of the important elements they need to know about.”[158]

However, parents interviewed by Payot’s team perceived the right decision as a decision that is supported by a medically competent team.[159] What are the implications of Payot *et al.’*s conclusions for the construction of ethical dilemma in the NICU? In other words, if parents and neonatologists have different perceptions of what constitutes a “right” – ethical – decision could they also have conflicting perception of what constitutes an ethical dilemma?

Winnifred Ellenchild Pinch’s research into parental perceptions of ethical decision-making in NICU suggests that they do.[160] Parents interviewed by Pinch expressed their decision-making dilemmas as relating to breast-feeding, balancing their presence in the NICU with other on-going family responsibilities and “keeping their lives

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[156] Payot *et al. supra* note 144 at 1492.
[157] *Ibid.* at 1493. See also P. Alderson, J. Hawthorne & M. Killen, “Parents’ Experiences of Sharing Neonatal Information: Consent, Cost and Risk” (2006) 62 Social Science & Medicine 1319, for similar conclusions reached in a different neonatal context.
[158] Payot *et al. supra* note 144 at 1493.
[159] *Ibid.* at 1496.
[160] Pinch, *supra* note 1 at 187.

on hold to accommodate whatever neonatal outcome resulted from the experience."[161] In a landmark chronicle of their child's course in the NICU, Robert and Peggy Stinson wrote on the day they learned of Peggy's low lying placenta and her chances to hemorrhage or deliver prematurely:

> For us the top priorities are: 1. preserving reasonably normal family life for child we have now and for ourselves 2. having a second healthy baby. Possible conclusion: these priorities perhaps not best served by preserving *this* pregnancy. [162]

The Stinsons' list of possible options to preserve these two priorities included abortion. Through these medically uncertain times, Peggy wrote: "What makes me cry most readily are thoughts of Jenny [the couple's first child]."[163]After deciding against aborting Andrew – "We couldn't go through with it – who knows exactly why. Is it the movement of the baby inside, the baby who is not enemy but innocent victim?"[164] – Peggy Stinson went into premature labor and delivered what she thought would be a stillborn infant. She later learned that her son has been stabilized and listened numbly to a conversation about the baby's chances of survival. As he left her bedside, one of her obstetricians told her offhandedly:

> … that he would give me a shot to dry up my milk. "You won't be nursing this baby," he said. That started the tears again. "Let's wait," I answered, and he shrugged his shoulders in the doorway and went away. I wondered at the power of my own fanaticism – as long as a baby existed at all, I couldn't give up the possibility of nursing it.[165]

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[161] *Ibid.*
[162] Robert Stinson & Peggy Stinson, *The Long Dying of Baby Andrew* (Boston: Atlantic – Little, Brown, 1983) at 14. Their son Andrew was born at 24 weeks gestation weighing 800 grams.
[163] *Ibid.* at 13.
[164] *Ibid.* at 18.
[165] *Ibid.* at 24.

Peggy Stinson's narrative of the ethical struggles she felt as health care professionals tried to save Andrew's life falls in line with Pinch's empirical observations of the moral experience of parents in the NICU whereby parental decisions are rooted in the broader context of their lives as opposed to the neonatologists' narrower focus on the medical management of the premature infant.

Other narratives of premature labor and delivery can be found in Helen Harrison *The Premature Baby Book.*[166] Contributors to Harrison's guide often relate conflicting values surrounding the care of their premature infant but rather than arising between themselves and their child's care givers, these conflicts arise internally and pertain to their ability to bond through the incubator's wall, their fear of holding their baby, their unwillingness to breastfeed or their guilt toward their older children and family members. In a moving narrative, neonatologist Annie Janvier relates her feelings of fear and anger following the birth of her daughter Violette at 24 weeks and 5 days. She writes:

> "I loathed visiting the neonatal intensive care unit while she was unstable. I hated being encouraged to participate in her care. I visited because I felt I had to show the nurses and social workers that I was a normal parent who was bonding." [167]

The author concludes by noting that mothers usually say yes when asked to participate because they are "drowned in guilt."[168]

The avenues of ethical dilemmas reported in the medical and bioethical literature may seem exhaustive or at least reflect a reasonable range of ethical queries arising in the

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[166] Harrison, *supra* note 151 (generally).

[167] Annie Janvier "I'm only punching in" (2007) 161 (9) Archives of Pediatrics and Adolescent Medicine 827.

[168] *Ibid.*

care of sick newborns. However, parental involvement in ethical dilemmas can only be meaningfully explored if ethical dilemmas are identified by parents in light of their experience in the NICU. When what is *reported* by medical or academic observers as ethically problematic passes as what *is* ethically problematic in the NICU, we are limited to a one-sided conception of what is ethically charged at the child's bedside. Not only do parental voices need to be considered in the unraveling of ethical dilemmas, but they must be able to participate in the determination of what constitute ethical dilemmas in the care of their infants.

Returning to legal pluralism and internormativity, putting health care professionals' focus on medical management and parental focus on the management of their personal lives side by side, we can see the burgeoning of an internormative dynamic whereby parents, caught up in their own personal struggles and grief, appear disengaged from day-to-day medical decision-making.[169] This leaves a void in the surrogate decision-making model favored by formal legal rules and, as we will see in chapter 4, creates the conditions for an accommodation of the shared decision-making model based on the lived experience of parents and health care professionals in NICU.

Withdrawing life sustaining support

Ethical dilemmas in the NICU are not exhausted once treatment is initiated. The seemingly clear definition of treatment avenues according to gestational age is everything but.[170] The CPS/SOGC Guidelines must be tempered by the CPS Guidelines on treatment

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[169] Pinch, *supra* note 1 at 202; Janvier, *supra* note 167.
[170] *Supra* note 130.

decisions regarding infants, children and adolescents.[171] The CPS Statement provides further guidance on the circumstances in which withholding treatment might be in a child's best interest. Unlike gestational age, the CPS guidelines are not easily defined and call for an even deeper ethical reflection on the meaning and purpose of life, death and illness. The CPS recommends that treatment be withheld only if there is "irreversible progression to imminent death", if life will be "severely shortened regardless of treatment and the limitation … of interventions will allow greater palliative and comfort care," or if life will be "filled with intolerable distress and suffering that cannot be prevented or alleviated."[172]

As Kate's story shows, prematurity-related morbidity is ongoing throughout infancy. Once a premature newborn has been resuscitated, her prognosis may be so dismal that withdrawal of life sustaining treatment appears to be in the child's best interest.[173] The CPS guidelines for withholding treatment apply equally to the withdrawal of treatment and force similar ethical quandaries. Ethical dilemmas surrounding the withdrawal of life sustaining support may occur several times over the course of an infant's stay in the NICU and may be made partially or conditionally. For instance, parents and caregivers may decide to limit treatment rather than withdraw it – as would

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[171] CPS Statement, *supra* note 62.

[172] *Ibid.* at 102.

[173] Resuscitating an infant marginally viable to withdraw treatment once it has been deemed futile is termed "trial of therapy." As a therapeutic approach, it is thought to reduce the uncertainty of treating extremely premature infants. For a discussion of the ethical implications of trial of therapy, read Nancy K. Rhoden, "Treating Baby Doe: The Ethics of Uncertainty" (1986) 16 (4) The Hast Cent Rep 34-42. In France, the belief in the intrinsic dignity of all human beings, including critically ill or congenitally malformed newborns, leads neonatologists to reanimate all newborns regardless of gestational age or medical condition and decide subsequently if treatment should be withdrawn. This surprisingly conservative approach is corollary to the possibility of withdrawing treatment at any time and in some cases, to administer drugs for the purpose of ending the life of the newborn. See Orfali, *supra* note 115 (generally) and Hurlimann, *supra* note 87 at 28-30.

have been the case if Kate's parents and caregivers had decided to provide continuous positive airway pressure (CPAP) but withhold ventilation or to treat aggressively but withhold cardio-pulmonary reanimation (CPR).[174] The internormative and ethical implications of neonatal therapies for extremely premature infants will be explored in further details in chapter 5 using mechanical ventilation and total parenteral nutrition (TPN) as examples.

The ethical challenges presented by decisions to withdraw treatment are complex and multi-dimensional. As a result, they give rise to normative interactions between decision-making agents and stakeholders. First, withdrawal decisions are omnipresent through a child's medical course in the NICU. Tertiary care of newborn children is, by definition, life-sustaining or life-saving and often both in turn.[175] It follows that every treatment decision, no matter how minor, may amount to a decision for or against withdrawal of treatment. [176]Secondly, prognostic uncertainty and the medical instability of NICU patients mean that an infant previously thought "on the mend" or "out of the woods" can start a rapid downward spiral towards mortality or severe morbidity; conversely, children thought "at death's doorstep" can make regular progress until discharge.[177] Finally, if in accordance with the CPS Statement on treatment decisions, parents and caregivers must come to a shared decision on the definition of a life "filled with intolerable distress and suffering," the process of reaching an acceptable common

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[174] Another example of treatment limitation (as opposed to withholding treatment) can be found in Anspach, *supra* note 69 at 108 (baby suffering from complex congenital malformations, decision to support with oxygen but withhold ventilatory therapy, baby died shortly after admission to the tertiary care center).

[175] CPS Statement "Levels of Neonatal Care" *supra* note 140 at 304.

[176] See Gordon B. Avery, "Futility Considerations in the Neonatal Intensive Care Unit" (1998) 22 (3) Seminars in Perinatology 216 at 216.

[177] See "They saved his life right in front of my eyes," City, *The Ottawa Citizen* (23 February 2007) F1.

ground can be fraught with controversy if decision-makers disagree on the scope of any of the terms found in the sentence. How “filled” is “filled”? Is “intolerable” an objective medical definition of a subjective personal one? To what extent should emotional and psychological “distress and suffering” be considered? Answering these questions puts the dynamics of internormativity in gear by requiring the expression of each decision-maker’s position on the meanings and purpose of life, illness and suffering. Rooted in each individual’s moral, cultural, religious and social substrata, answers reach deep into what makes individuals think and act the way they do and produce a normative order distinct yet integrated to the systemic order of enacted law.[178]

3.2 Concluding remarks

Bioethical dilemmas surrounding the care of NICU patients arise when several solutions or treatment avenues appear equally good or equally bad. When stakeholders in a bioethical dilemma have irreconcilable views on what constitutes the good and the bad, bioethical conflicts arise.[179] Disagreements on what constitute the good, the bad, the right or the just are not only rooted in diverging values but can stem from the relative importance put by decision-makers on different goals and expectations. The multiplicity of diseases and simultaneous treatments in neonatal intensive care, combined with outcome uncertainty, give every treatment an ethical dimension.[180]

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[178] Rocher, *supra* note 7 at 134 on the distinction between “ordre juridique” and “ordre normatif.”
[179] Shelp, *supra* note 85 at 8-12; Pinch, *supra* note 1 at 25; see generally Fadiman, *supra* note 108.
[180] Pinch, *supra* note 1 at 22-23; Arthur Caplan & Cynthia B. Cohen, “Imperiled Newborns” (1987) 17 (6) Hast Cent Rep 5 at 6.

Bioethical dilemmas surrounding neonatal intensive care are by no mean limited to what arises in the medical treatment of critically ill infants. Although my thesis voluntarily focuses on ethical dilemmas arising at the infant's bedside, broader bioethical enquiries reported in the literature span issues of resource allocation at the institutional level, philosophical reflection on what is morally required treatment, public policy debates about health spending and social responsibility toward people with disabilities.[181] The complexity and omnipresence of areas of bioethical questioning expose the NICU as a fertile environment for the emergence of normative interactions and situations of legal pluralism. Yet, the potential for ethical conflict presupposes the existence of a shared space, an ethical corral, where decision-makers can engage in ethical discussion and stake their ethical landmarks. Ethnographic research on decision-making in the NICU suggests that the existence of ethical issues by no mean guarantees that decision-making will be shared. The next chapter will explore how parents and caregivers engage in ethical decision-making and draw a comparative picture of the theory of shared decision-making according to Canadian law and practice guidelines and the reality of parental agency in ethical decision-making.

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[181] Pinch, *supra* note 1 at 35. Moreover, the academic approach to each ethical query differs according to the disciplinary background of the writer.

Chapter 4: Does the shared decision making model reflect parental experiences?

Parental interest in ethical decision-making has not always been recognized in pediatric intensive care medicine. Medical culture and legal obligations have in turn curtailed parents' involvement in decision-making concerning their children.[182] A review of paternalism in neonatology will be followed by a reflection on the models of parental involvement – the consent model and the assent model – identified by empirical research as predominant in neonatal intensive care environments.[183] We will see that the construction of informed consent and ethical dilemmas between parents and health care professionals redefines the decision-making domain, calling upon partners in shared decision-making to interact in the margins of their legally defined roles. These *marginal* interactions are the foundation of critical legal pluralism and illustrate how law is created by its subjects rather than merely applied to them.

4.1 Shared decision-making: Influences and obstacles

Paternalism: A hovering legacy

A study of internormativity in the NICU must take stock of long standing normative influences that wield an impact on decision-making, starting with a culture of

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[182] Harrison, *supra* note 151 at 166. Generally: Stinson & Stinson, *supra* note 162.

[183] In selecting relevant empirical research, I chose to focus on medical environments technologically similar to Canada. However, it should be noted that socio-cultural differences, as well as health care funding schemes may affect neonatal outcomes significantly. A concise and informative summary of ethical issues in the NICU can be found in Kathleen Cranley Glass, "Ethical Issues in Neonatal Intensive Care: Perspectives for the Neurologist" (2002) 9(1) Seminars in Pediatric Neurology 35.

medical paternalism.[184] If medical paternalism is not the only normative influence rooted in the culture and organization of intensive care medicine, it is, in my view, the most relevant to explain how decision-making models have emerged in the NICU.[185] As the value placed on individual autonomy increased and reached a new stature as "the morally relevant feature of personality,"[186] initiatives to limit patient autonomy, no matter how well-meaning, have been expulsed from medical practice.[187] In the NICU, the extreme vulnerability of patients and the emotional anguish of parents have prevented the elimination of paternalism from the decision-making process. Paternalist attitudes among physicians have an appreciable impact on internormativity in the NICU, as a review of ethnographic studies on decision-making will later reveal.

In 1973, when neonatologists Duff and Campbell published their study on moral and ethical dilemmas in the intensive care nursery,[188] the weight placed on parental involvement in the care of their children was considered "liberal policy".[189] Parents were encouraged to "see and handle their babies" and were "often present when some infant

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[184] Paternalism can be defined as "an interference with the liberty of action or freedom of information of another for the purpose of promoting the interest of that individual." Carson Strong, "Paternalism in the Neonatal Intensive Care Unit" (1984) 5 Theoretical Medicine 105 at 105. Strong's preferred definition is considered "narrow" because its underlying purpose is the welfare of the patient. Paternalism understood broadly justifies paternalism – or the substitution of the physician's autonomous decision to her patient's – by the promotion of the patient's future autonomy, see Mark Strasser, "The New Paternalism" (1988) 2 (2) Bioethics 103 at 104. By both accounts, paternalism is benevolent and well-meaning. The purpose of this brief discussion of medical paternalism is to place it as a normative influence on decision-making and can accommodate both definitions.

[185] An exhaustive review of cultural and organizational normative influences on life-and-death decision making in the NICU can be found in Anspach, *supra* note 69 (generally).

[186] See Virginia A. Sharpe, *supra* note 115.

[187] Although some patients do not have the capacity to understand the information relevant to a treatment decision, they must still be treated with respect as autonomous agents. When decisions are made by a surrogate, the patient's autonomous agency is placed in the capable hands of the surrogate, not replaced by the surrogate's. (see Etchells *et al. supra* note 79; see also Christine Harrison *et al. supra* note 98.

[188] Raymond S. Duff & A.G.M. Campbell, "Moral and Ethical Dilemmas in the Special-Care Nursery" (1973) 289 N Engl J Med 890.

[189] *Ibid.* at 249.

[was] critically ill or moribund."[190] While this approach to neonatal care may have been progressive by contemporary standards, final decision-making was the prerogative of neonatologists.[191] Placed at the nexus between the patient, the staff and the parents, the neonatologist held a privileged standpoint. In addition, medical decisional authority spared parents the heavy burden of life-and-death decisions.[192] The dearth of ethnographic studies on parental involvement in ethical decision-making contemporary to Duff and Campbell prevents us from presenting a clear depiction of the extent of parental involvement prior to the advent of family-centered care and the consumer revolution of the 1970s.[193] However, ethnographic studies of physicians' attitudes toward critically ill newborns confirm the *ad hoc* approach adopted by the Yale-New Haven institution where parental involvement was allowed by attending neonatologists on a case-by-case basis, in

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[190] *Ibid.*

[191] To compare standards, I suggest reading Duff and Campbell's article in parallel with R.M. Forrester, "Salvage" (1965) January 30 The Lancet 262 (MEDLINE), where the author, a pediatrician, discusses three cases that caused him much soul searching, two of them concerning newborns with congenital malformations. It should also be specified that Raymond Duff advocated giving parents wide latitude in end-of-life decision making because they ultimately bear the burden of caring for a disabled child, see Duff & Campbell, *supra* note 188 at 893-894.

[192] Duff & Campbell, *supra* note 188 at 250. The argument that parents desire to be spared from decision-making authority in life-and-death decisions is still advanced in today's autonomy context, see Martha Montello & John Lantos, "The Karamazov Complex: Dostoevsky and DNR Orders" (2002) 45(2) Perspectives in Biology and Medicine 190.

[193] Family-centered care is a treatment philosophy that promotes collaboration between treating team, patients and their families through open communication, respect and empowerment of the family. The precepts of family-centered care in pediatrics recognize that families are a constant in a child's life whereas health care personnel come and go. Family-centered care in the NICU, when well integrated to an institution's standards of practice and guidelines, is believed to improve outcomes by leading to shorter hospital stays, fewer readmissions, better breastfeeding outcomes, reduced parental stress and increased staff satisfaction. Michael S. Dunn *et al.* "Development and Dissemination of Potentially Better Practices for the Provision of Family-Centered Care in Neonatology: The Family Centered-Care Map" (2006) 118 November Pediatrics s95 at s96. Many question if the integration of the precepts of family-centered care in pediatrics is reflected in medical practice or if it corresponds to what families needs, see Mary F. Peterson, Jayne Cohen & Virgil Parsons, "Family-Centered Care: Do We Practice What We Preach?" (2004) 33 (4) Journal of Obstetric, Gynecologic and Neonatal Nursing 421; Elizabeth Galvin *et al.* Challenging the Precepts of Family-Centered Care: Testing a Philosophy" (2000) 26 (6) Pediatric Nursing 625.

function of the best interest of the child, the family's situation and institutional/professional constraints or guidelines.[194]

Physicians' discretion in treatment decisions for critically ill newborns drew interest and criticism from bioethical literature but this interest was directed at the ethical implications of making life-and-death decisions and quality-of-life judgments in an area of medical science fraught with uncertainty and prognostic perplexity.[195] Parents were rarely mentioned and if they were, it was to examine the influence of their opinion, socio-economic background or reactions on decisions made by neonatologists.[196] Parental involvement in ethical decision-making surfaced with force in 1981 with the Baby Doe controversy and ensuing legal reforms.[197] The Baby Doe amendments to American child abuse and discrimination legislation imposed legal duties on doctors and hospitals to treat disabled children and limited parental ability to refuse treatments.[198] The Baby Doe regulations created a litigious environment oriented toward the protection of institutional

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[194] I drew on two important and widely cited studies to reach this conclusion: Diana Crane, *The Sanctity of Social Life: Physicians' Treatment of Critically Ill Patients* (New York: Russell Sage Foundation, 1975) and Todres *et al.* "Pediatricians Attitudes Affecting Decision-Making in Defective Newborns" (1977) 60 Pediatrics 197, followed by I. David Todres *et al.* "Life-Saving Therapy for Newborns: A Questionnaire Survey in the State of Massachusetts" (1988) 81 Pediatrics 643, and I. David Todres *et al.* "Moral and Ethical Dilemmas in Critically Ill Newborns: A 20-Year Follow-Up Survey of Massachusetts Pediatricians" (2000) 1 Journal of Perinatology 6.

[195] Pinch, *supra* note 1 at 36.

[196] See generally Crane, *supra* note 194 and Todres *et al. supra* note 194.

[197] See John A. Robertson, "Extreme Prematurity and Parental Rights After Baby Doe" (2004) July-August Hastings Center Report 32 at 33. Baby Doe was a newborn with Down syndrome whose duodenal artresia was left uncorrected and caused his death. Initially, the Baby Doe regulations were enacted by the Department of Health and Human Services and required institutions receiving federal funding to report cases of "discrimination in treatment based on handicap." Reports of discrimination initiated federal oversight of medical records. The original regulations were struck down and re-written by the Reagan administration to be less intrusive. After much litigation, the Child Abuse Amendments of 1984 ended direct federal intervention in neonatal intensive care and attached child abuse funding to the creation of "infant care review committees" to ensure that disabled newborns were protected against treatment discrimination based on disability.

[198] *Ibid.* at 34.

and professional interests rather than on the involvement of parents.[199] The Baby Doe environment effectively imposed a new form of paternalism in neonatal intensive care, this time a *legal* paternalism, whereby parental exercise of decisional autonomy on behalf of their sick infant became limited by institutional restrictions aimed at avoiding legal controversy. The underlying assumption of paternalism, seeing the interest of the patient as better served by a chosen set of values rather than the patient's own, substituted parental autonomy for institutional legal autonomy.[200]

Presently, a certain form of paternalism is still advocated as morally permissible in North American NICU. European countries still hold fast to a paternalistic model informed by theories on parents' guilt and necessary medical expertise.[201] Lingering paternalistic attitudes in shared decision-making surface in the CPS Statement[202] with its emphasis on the medical determination of best interest reached through adequate "information" against which family "issues" must be managed. First, paternalistic attitudes upholding the primacy of the medical norm affect shared decision-making by determining in which cases informed consent will be obtained and by eliminating the possibility of ethical dilemmas when treatment decisions are medically uncontested.[203] Second, paternalistic attitudes affect the management of prognostic uncertainty by

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[199] The Baby Doe regulations never had force of law in Canada and their effect on the legal environment of the NICU was mostly felt in the United States. I mention the Baby Doe regulations because I believe that the American legal environment had an impact on the behavior and expectations of Canadian neonatologists and hospital administrators. The proximity of the United States, geographically but also in terms of therapeutic armamentarium and medical culture, makes this influence probable. Empirical research on the legal environment of Canadian NICUs is lacking.

[200] See Orfali, *supra* note 115 at 2013.

[201] See Strong, *supra* note 184 for a justification of paternalism based on the neonatologist's role as patient advocate and parental response; see Orfali, *supra* note 115 at 2011 for a reflection on medical paternalism in European countries.

[202] *Supra* note 62.

[203] Orfali, *supra* note 115 at 2014

defining unilaterally what constitutes medical uncertainty and conversely, medical certainty.[204] In the notoriously unpredictable environment of the NICU, determining the statistical threshold where outcomes become “certain” or treatments become “futile” are normative pronouncements. The characteristic subjectivity of futility verdicts is cause for concern when the normative influences shaping physicians’ conception of futility are assimilated to objective information whereas parental influences are seen as subjective “issues”.[205] Finally, the CPS’ conceptualization of decisions as either “medical” or “parental” limits the information available to parents to what is considered relevant to the parental realm of shared decision-making.[206] Information limitation has direct implications for informed consent and has a determining influence on models of surrogate decision-making found in the NICU.

Decision-making in NICU literature: Redrawing informed consent

In neonatal intensive care, medical decisions are taken quickly and often. The importance of parental involvement, while enshrined by Canadian law and integrated into medical practice guidelines, is reflected differently in different establishments. If medical caregivers must obtain informed consent from surrogate decision-makers, approaches vary among care settings as to how information is shared with parents and how consent is obtained.[207] While the scope and nature of parental involvement remains theoretically the same, organizational culture and power dynamics affect the quantity and quality of

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[204] *Ibid.*

[205] See James L. Bernat, “Medical Futility: Definition, Determination and Disputes in Critical Care” (2005) 2 Neurocritical Care 198-205. See also John Lantos, “When Parents Request Seemingly Futile Treatment for their Children” (2006) 73 (3) The Mount Sinai Journal of Medicine 587, where the author breaks down the concept of futility into four components: power, money, trust and hope.

[206] Orfali, *supra* note 115 at 2010.

[207] Anspach, *supra* note 69 at 87.

information shared with parents. Often, the quality and quantity of information dispensed speak directly to the parents' perceived ability (or inability) to process the requirements of informed consent and has a direct impact on the definition of their role in shared decision-making. Guillemin & Holmstrom's sociological account of the NICU environment tells the story of Darlene, an infant whose course of treatment was directly influenced by the staff's perception of her family's ability to understand her medical condition and her care requirements. [208] Darlene's mother and grandmother were perceived as volatile and not open to reasonable argument. Instead of discussing withdrawal of treatment with the child's family, a complex pattern of misinformation and therapeutic momentum led the medical staff to give the family hope in Darlene's future even though her prognosis remained dismal. Darlene was transferred from the NICU to the general pediatric ward presumably before she could withstand the lower nurse-to-patient ratio and the general unit's "less heroic standards."[209] Shortly after the transfer, Darlene went in respiratory failure because her oxygen hood had not been properly reconnected and died of viral pneumonia a month later.[210] Darlene story shows us how parental involvement can be redefined and re-drawn by health care providers within the boundaries of informed consent requirements. Darlene's family was involved in numerous decision-making conferences but Darlene's course of treatment was altered to avoid confrontation over a possible withdrawal of treatment. But while Darlene could have received maximum care, she would remain a sick child requiring complex care at home, care that the staff did not think her family could provide.

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[208] Guillemin & Holmstrom, *supra* note 114 at 198-225.

[209] *Ibid.* at 204.

[210] *Ibid.* at 222.

As Darlene’s case demonstrates, legally plural interactions also emerge when legally relevant information is manipulated to redefine parental roles within the boundaries of formal law, in this case formal rules of informed consent. Informed consent requires a trusting relationship between the providers of information and those who need to make a decision based on that information. The breakdown of trust between Darlene’s family and her medical caregivers lead the staff into a modified model of informed consent where, in the absence of trust, staff chose treatment avenues that would not antagonize Darlene’s family. Transferring Darlene to the general pediatric ward amounted to a withdrawal of treatment but did not involve broaching the withdrawal question with the family; moreover, it capitalized on the family’s denial of Darlene’s medical needs by suggesting that she was improving enough to eventually be discharged home.

While cases like Darlene’s are unusual, redrawing the boundaries of informed consent – and consequently shared decision-making – is a common occurrence in neonatal intensive care. Anspach and Payot *et al.* both report a duality of informed consent models sitting at opposite ends of a continuum.[211] At one end, the consent model – as termed by Anspach – sees parents as integral players within the medical decision-making process and recognizes their autonomy and responsibility. At the other end of the spectrum, the assent model is built around the necessity to elicit parental assent rather than obtaining consent. The assent model, whether or not it is termed as such, is widely

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[211] Anspach, *supra* note 69 at 87; Payot *et al. supra* note 144 at 1490;

reported as the norm in intensive care nurseries.[212] The following sub-sections will discuss in turn the consent model and the assent model before reflecting on their impact on surrogate decision-making in the NICU.

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[212] See e.g. Anspach *supra* note 69, Pinch, *supra* note 1, Orfali, *supra* note 115, Payot *et al., supra* note 144. See also Hazel E. McHaffie, Andrew J. Lyon, & Robert Hume, "Deciding on treatment limitations for neonates: the parents' perspective" 160 European Journal of Pediatrics 339.

The consent model

In a consent model, information about the child's condition, associated mortality or morbidity risks and sequelae is provided, allowing parents to choose from a range of treatment options associated with a range of prognostic outcomes. While parents may be supported as they face these difficult decisions, they are expected to manage their child's uncertain diagnosis and assume the decision-making process.[213]

The consent model presents treatment options to parents – including decisions to withhold or withdraw treatment – in a non-judgmental way and makes parents integral to medical decision-making. However, as Anspach points out, it carries the risk of seeing parents make decisions that are unpopular with the child's medical caregivers.[214] Moreover, the diagnosis of diseases and the choice of appropriate treatment are both within the realm of medical expertise. In the presence of a complex and powerful "therapeutic armamentarium," the possibility of offering an array of interventions may be impossible or extremely difficult.[215] Yet, rank-ordering treatment options on behalf of parents can take the appearance of information manipulation and affect informed consent accordingly.[216] Finally, time constraints and emergencies can cause parents to abdicate decision-making responsibility or report feeling pressured by the speed of the process.[217] In the fast-paced environment of the NICU, informed consent – understood as including a

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[213] Anspach, *supra* note 69 at 87.

[214] *Ibid.* at 90. Anspach gives the example of a withdrawal decision made on behalf of a dying ventilator-assisted infant. Parents were given two sets of options: (1) being present at their child's bedside and holding him as he died or being called once their child had died; (2) turning off the ventilator right away or letting the child die while on the ventilator. Parents chose to be absent but maintain ventilator support. This decision was reported to be difficult to accept for the medical personnel.

[215] Avery, *supra* note 176 at 216 [abstract].

[216] See Ruth Faden & Tom Beauchamp, *A History and Theory of Informed Consent* (New York: Oxford University Press, 1986).

[217] McHaffie, Lyon & Hume, *supra* note 212 at 343.

reflection on one's feelings, role and priorities in light of relevant medical information – may be impossible to obtain.

Canadian law on surrogate decision-making assigns parents – defined as autonomous and independent agents taking full responsibility for decisions made in the best interest of their child – to the consent model. The challenges of upholding ideals of autonomy and best interests in a situation of interdependence are not acknowledged, leaving agents in the decision-making process to re-invent the interactional language of law in a mutually intelligible manner.

The assent model

The recognition that recommending indicated therapy is an integral part of a physician's duty – not to mention the main reason why patients seek the assistance of a physician – has opened the door for an adjustment of the consent model that acknowledges the patient's dependence on the physicians' grasp of medical information, particularly in situations where timing is critical.

In the assent model, treatment options are presented to parents in a manner that frames or shapes their decision-making powers.[218] Parental agency is reported to be limited first by constraining participation in decision-making. Staff meetings and parents meetings are held consecutively to avoid confusing parents with conflicting opinions. The laudable purpose of presenting a united front translates into the exclusion of parents from

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[218] Anspach, *supra* note 69 at 92; Payot *et al. supra* note 144 at 1490.

professional discussions and from the ethical dilemmas that might have arisen in the course of these discussions. Secondly, parental agency is limited by the range of choices previously agreed upon by health care professionals. Coming back to Kate's case[219], staff meetings about her care might have touched on the possibility of limiting treatment following her spells of respiratory failure but Kate's parents would not have been consulted on that possibility unless the staff had agreed that limiting treatment was a reasonable option.[220] In other words, parents are not consulted about the continuation of treatment unless discontinuation is considered.[221] Parents enter the corral of shared decision-making by invitation only, once the fence has been installed by health care professionals.

4.2 Deciding on behalf of children: May the real surrogate stand up

Empirical research and parental perceptions of ethical decision-making

It is not enough to argue that parents find themselves in the periphery of ethical decision-making, we must also examine to what extent this exclusion meets their needs and expectations, those of health care professionals and the demands of the intensive care environment. If legally pluralistic situations emerge from the inability of formal law to penetrate certain areas of human interactions,[222] we must delve into the needs and expectations of those who give life to these interactions. How does the law pertaining to surrogate decision-making and autonomy fail to meet the needs of ethical decision-

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[219] Above at 57-58.

[220] Hazel E. McHaffie *et al.* "Deciding for imperiled newborns: medical authority or parental autonomy?" (2001) 27 Journal of Medical Ethics 104 at 105.

[221] This conclusion is generally reported by Anspach, Orfali, Payot *et al.* and Pinch.

[222] André-Jean Arnaud, *supra* note 30 at 248-249. See also generally Lon L. Fuller, "The Law's precarious hold on life" *supra* note 73.

making in the NICU, and particularly, how do parents perceive their limited role in ethical decision-making? From a pluralist perspective, parents' attitudes toward their restricted role in decision-making inform what role law plays in defining parental behavior and at which point formal law gives way to plural, self-created, normative interactions.

By their nature, ethnographic studies provide extensive descriptions of social and cultural phenomena in a small number of cases. So while ethnographic conclusions cannot be generalized to all families in all neonatal intensive care units, they can nonetheless offer a window into the sheltered world of the NICU. The following analysis of decision-making will draw from four ethnographic research projects conducted in NICU.[223] Parental experiences related in these research projects will reveal a marked difference between the surrogate decision-making model offered by Canadian law, the shared decision-making model offered by Canadian health policy and the assent model reported by fieldworkers studying the NICU. How does parental experience fit within these three different accounts of decision-making and informed consent?

Anspach: Examining decisions directly

Renée Anspach's study of life-and-death decisions in neonatal intensive care presents data collected in two different intensive care nurseries over a period of sixteen months. The author spent twelve months in a major teaching hospital recognized as an elite institution in a large urban area, then conducted four months of comparative

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[223] Anspach, *supra* note 69; Pinch, *supra* note 1; McHaffie, *supra* note 212 and 220, and Orfali, *supra* note 115.

fieldwork in a sharply different institution, one providing government-funded acute care to the indigent.[224] Anspach's research goal was to study the process informing life-and-death decisions in the NICU by using the decisions as starting point and gathering information about the social context, participants and circumstances of each decision. Her research project presents a multi-dimensional account of actual decisions rather than hypothetical dilemmas.[225]

In both health care institutions, the life-and-death decision-making process followed a similar path. In both nurseries, the attending physicians were acknowledged to have formal and legal authority over life-and-death decisions. Consequently, they bore the ultimate responsibility of deciding what had to be done. Staff meetings gave health care professionals the opportunity to voice their concerns and reach consensus on the termination or continuation of life-support. Once professional consensus was attained, parents were consulted and encouraged to be with their babies when they died.[226] Anspach sociological viewpoint looks beyond the ethical/legal requirements of informed consent and surrogate decision-making and questions the *processes* whereby parents are informed and consent is obtained. She identifies several "organizational features of intensive care" placing parents in the "periphery of life-and-death decisions" and complicating the consent process to the point of making truly informed consent elusive.[227] She concludes that in both nurseries, the decision-making process is "organized to limit

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[224] Anspach, *supra* note 69 at 9-17.

[225] Surveys of life-and-death decision-making cited in this thesis use large-scale samples of physicians asked to comment on hypothetical dilemmas; see Crane, *supra* note 194, Todres, *supra* note 194.

[226] Anspach, *supra* note 69 at 18.

[227] *Ibid.* at 113-123. These organizational features are high technology creating spatial barriers, the rotation of health care professionals creating the barrier of time, the medical division of labor creating the barrier of hierarchy and the regionalization of neonatal care creating the barrier of geographic distance.

the options available to parents and to eliminate parents from some decisions altogether."[228]

Anspach's observations of parental responses to their exclusion from life-and-death decision-making relate a deep sense of frustration lined with resignation. When parents disagreed with decisions to treat their babies actively, they withdrew from the NICU rather than assert their wishes and create open conflict.[229] The effect of this coping mechanism saw parents disengage not only from the unit and the staff but also from their infant. By comparison, parents who were considered "medically sophisticated" tended to create more overt conflict before eventually withdrawing emotionally.[230] Parents also reacted to their exclusion from life-and-death decisions by challenging what staff viewed as routine procedures causing pain and discomfort, such as needle pricks and band-aids. Such attitudes tended to put parents on a collision course with their child's caregivers and cause yet more exclusion. Conflict also arose when parents disagreed with life-and-death decisions, although Anspach does not report any cases where treatment was withdrawn without the parents' consent.[231]

Because she studies decisions rather than decision-makers, tacit or implicit normative influences on the decision-making process are absent from Anspach's narrative. Moreover, the exclusion of parents from life and death decision-making is

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[228] *Ibid.* at 93.

[229] *Ibid.* at 132. The same withdrawal dynamic can be explored through the first-person narrative of Peggy Stinson in Stinson & Stinson, *supra* note 162 at 94-104.

[230] *Ibid.* at 133.

[231] Withdrawal decisions are made in the parents' absence but the act of withdrawing treatment is not performed until the parents agree. The author does tell of a case where caregivers, unsure if the child's mother would agree to the withdrawal decision, discussed the possibility of taking an infant off the ventilator in the mother's absence, see *ibid.* at 137.

reflected in Anspach's research purview: since she studies decisions as social acts and since parents are excluded from the decision-making process, their input does not figure prominently in her study. The limited insight into parental influence offered by Anspach is composed of physicians' accounts of the influence of parents on *their* decision-making. Health care professionals decide how and if they will let family-based normativity influence their decisions and dictate the terms and extent of parental participation in neonatal decision-making. As a result, Anspach's research presents some important limitations for this thesis in that it does not address overtly the parental experience of exclusion from decision-making, nor does it approach what goes – or should go – into life and death decision-making from a parent's perspective.

Pinch: Surprised by the lack of active involvement

Winnifred Ellenchild Pinch's longitudinal research enterprise targeted parental perceptions of ethical decision-making in the NICU. Her data was collected over three distinct phases that began prior to the infant's discharge (phase I) and pursued 6 months after discharge (phase II) and four year after discharge (phase III).[232] The purpose of her project was to "describe in detail the individual parental meaning attached to the more impartial morbidity and mortality rates for high-risk pregnancy and high-risk neonates."[233] As a longitudinal study, Pinch's research enterprise offers interesting insight into decision-making because it presents parental perceptions while immersed in ethical decision-making (phase I), shortly after discharge when they are still learning to cope with their NICU experience and life with a high-need infant (phase II) and four years later

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[232] Pinch, *supra* note 1 at xiii.
[233] *Ibid.* at xii.

(phase III) when once-statistical outcomes are becoming facts and parents are starting to look ahead to the future.

Pinch expresses surprise that despite highly publicized calls for more parental involvement, most parents did not perceive themselves to be decision-makers.[234] Parents signed informed consent forms and received up-to-date information on their child's state of health and treatment course but reported either "not having much of a choice" or expecting things to happen without their permission. One parent summed up: "We are not the ones trained for it."[235]

Finally, Pinch observes that critically ill newborns' dependence on skilled and sophisticated interventions led parents to abdicate decision-making authority willingly in favor of health care professionals.[236] Referring to parents' testimonies, Pinch identifies three factors contributing to this new "surrogate arrangement": the parents' compromised emotional and/or physical state, their estrangement from the newborn requiring care they cannot provide, and the NICU environment, including the authority and control exercised by health care professionals.[237] Parents remembered sharing information and having to sign informed consent forms but did not consider these procedures to be "decision-making.[238]

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[234] *Ibid.* at 356.
[235] *Ibid.* at 71-72
[236] *Ibid.* at 90. Pinch terms this abdication of responsibility in favor of the child's health care providers the "medicalization of parenting."
[237] *Ibid.* at 91.
[238] *Ibid.* at 356.

Pinch's research picks-up internormativity in the NICU where Anspach left it by including the analysis of parental voices as a secondary analysis to her study of ethical decision-making.[239] Though the author does not systematically identify particular normative influences on parental decision-making, she examines the moral reasoning of parents as the psychological dimension of ethical decision-making. One of Pinch's most interesting conclusions relevant to the study of internormativity is her observation that while parents considered themselves to be in conflict, their concerns seldom matched the prevalent ethical dilemmas addressed in the literature.[240] Throughout the three phases of Pinch's study, parents did not perceive themselves to be involved in ethical decision-making *while their child was in NICU.*[241] Moreover, in their pre-discharge interviews, parents did not object to this circumstance. Being comfortable with their role did not mean that this form of estrangement had no effect on their relationship with their child: parents also expressed "feelings of emptiness and [a] lack of fulfillment."[242] Only once they started living with the practical implications of these decisions – as discussed in their two post-discharge interviews – did parents start to object to their exclusion from ethical decision-making.[243]

McHaffie: Ethical decision-making as an integral part of parenting

The image of parents as being aware of their lack of involvement in ethical decision-making forces us to question whether the re-organization of the formal notions

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[239] *Ibid.* at 177-196.

[240] Pinch summarizes those dilemmas as the moral status of the newborn, treatment decisions for infants with compromised mental or physical status, locus of decision-making and the best interest standard. *Ibid.* at 187.

[241] *Ibid.*

[242] *Ibid.* at 74-75

[243] *Ibid.* at 187.

of surrogacy, autonomy and informed consent correspond to what parents expect from decision-making as their child lies between life and death. Recast in terms of internormativity, if law is a language of interactions and if legally pluralistic situations arise from formal (enacted) law's inability to meet the interactional needs of particular situations, is the existence of an alternative organization of surrogate decision-making an expression of parents' expectations from the decision-making process?

A research project conducted in Scotland revealed an interesting decision-making dynamic between parents and health care providers.[244] Hazel E. McHaffie's research project was conceived in two stages: the first stage investigated 155 nurses and physicians' thinking and practices ("consultants") and the second stage investigated the perceptions of the parents of 62 babies (108 parents) who died in the NICU following a decision to withdraw invasive treatment.[245] As Anspach, Pinch and Payot *et al.* observed in their own research, McHaffie's first stage interviews with consultants confirmed that withdrawal decisions are made in two distinct phases: a consensus is first reached among health care providers; this decision is then taken to the parents for consideration with or without a recommendation.[246]

The initial interviews with consultants revealed that only 3 percent of physicians and 6 percent of nurses thought that parents should make the "ultimate decision."[247] The

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[244] McHaffie, Lyon & Hume, *supra* note 212 and McHaffie *et al. supra* note 220. While this study was conducted in Scotland on a small sample of families, its principal conclusions fall in line with secondary observations made in many other studies from Canada (Payot *et al.*), the U.S. (Pinch, Anspach and Orfali) and France (Orfali).

[245] *Ibid.*

[246] McHaffie *et al. supra* note 220 at 105.

[247] *Ibid.*

majority of respondents (58 percent of physicians and 73 percent of nurses) reported a "joint approach to the actual decision."[248] It is interesting, from a human interaction point of view, to notice the apparent differentiation between the medical decision-making processes whereby a consensus is reached among consultants and what is termed "the actual decision." Such differentiation points to the purpose of the joint approach which is to spare parents the burden of making withdrawal decisions. Consultants recognize the value of parental involvement but hold fast to the belief that withdrawal decisions are too heavy for parents to make on their own. Physicians and nurses engage in the decision-making process before inviting parents to share in "the actual decision." McHaffie thus concludes that decisions to withdraw treatment are made by the medical team with or without the parents.[249]

If this conclusion is not surprising in light of Pinch and Anspach's accounts of decision-making in neonatal intensive care, it becomes more interesting when compared to the results of the second phase of the same study which features interviews with parents. 56 percent of parents perceived that the decision had been theirs, breaking down between 42 percent who believed that the decision had been theirs alone and 14 percent who believed that the decision had been shared with health care professionals. Parents who believed that the decision had been theirs admitted to relying heavily on medical information or treatment recommendations provided by their child's caregivers. Only one father thought that the decision had been too burdensome but that parental involvement was theoretically right. Parents simply perceived treatment withdrawal decisions, no

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[248] *Ibid.*

[249] *Ibid.*

matter how difficult, to be a part of their parenting responsibilities.[250] When asked in retrospect if the right person had decided and if the decision was substantially right, the majority of parents responded affirmatively. Parents who expressed lingering doubt about the decision-making process were concerned by “the lack of concrete evidence of a poor prognosis and the distressing nature of the dying process.”[251]

When placed side-to-side, McHaffie’s statistics[252] about the identity of the decision-makers show a variation between the perceptions of the health care professionals and those of the parents as to who in fact made a withdrawal decision. Such variation in perceptions is explained by the 42 percent of parents reporting accepting full responsibility for the withdrawal decision whereas only three percent of doctors and six percent of nurses believed that decisions should be made by the parents alone.[253] McHaffie suggests several possible reasons to explain this disparity between parents’ perceptions and physicians’ descriptions of the decision-making process, including the turbulence of emotions surrounding the birth of a marginally viable child and the parents’ reliance on medical information which may colour physicians’ perceptions of their own influence. Still, the reason that seems most plausible in light of similar ethnographic studies is that parents may not be aware of previous discussions and decision-making endeavors by health care professionals.[254] Accordingly, any parental decision falling in line with a previously-reached medical consensus could be reported as taken independently or jointly, in function of the parents’ awareness of medical involvement.

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[250] McHaffie, Lyon & Hume, *supra* note 212 at 341-342; McHaffie *et al. supra* note 220 at 105-106.
[251] McHaffie *et al.supra* note 220 at 106.
[252] Above at 89-90.
[253] *Ibid.* at 105.
[254] *Ibid.* at 107

Considering the emotional turmoil that characterizes ethical decision-making and the imbalance of medical authority between parents and consultants, parents' unawareness of the dynamics of medical decision-making should not come as a surprise to healthcare professionals. The fact that parents remain unaware of these dynamics to the point showed by McHaffie's research (42 percent of parents *versus* 3 percent of physicians reported parents' sole involvement in decision-making) suggests that healthcare professionals recognize both the importance of parental involvement in ethical decision-making and their own experience and authority over medical facts. The "language of interactions"[255] thus created is based on a manipulation of information – no matter how well-meaning – destined to give the illusion of parental autonomy while overcoming it.[256] What is the process whereby information is communicated in a manner likely to satisfy both the demands of medical authority and patient autonomy? The next section will turn to the ultimate influence of parents on ethical decision-making and the process whereby ethical dilemmas are managed to reduce the influence of non-medical actors.

Orfali: The elimination of ethical uncertainty

Noting that academic literature on treatment limitations and patient autonomy did not address the crucial question of outcomes, Kristina Orfali's comparative research

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[255] Fuller "Human Interaction" *supra* note 24 at 5.

[256] McHaffie believes that there is a form of misbalance between medical influence on withdrawal decisions and parental autonomy but that in light of the quantity of medical information required to make a withdrawal decision, this misbalance does not necessarily reflect negatively on the decision-making process. She concludes similarly that if the recommendation of a preferred course of treatment by consultants can be construed as information manipulation, this manipulation should not be perceived negatively if, in hindsight, parents are satisfied by the decision and the process. McHaffie *et al.supra* note 220 at 107.

project addressed the significance of parents' role in the decision-making process by studying the link between parental intervention and neonatal outcomes. She questioned whether parental interventions actually affected neonatal outcomes or if decisions were "essentially based on strictly medical criteria."[257] Her approach relies on a case-based comparative examination of decision-making in two "technologically similar but culturally and institutionally different contexts: France and the United States."[258] The contrasting point between France and the United States is their respective approaches to patient autonomy. Orfali expected to compare outcomes from decisions made by physicians in France, where a paternalist model still prevails in cases where patients are unable to consent for themselves, and decisions made by proxies in the United States, where the autonomy model leads the legal recognition of the surrogate's role in medical decision-making.[259] Orfali predicted that marked difference between the outcomes of children whose parents had made medical decisions and children whose medical course had been entirely determined by physicians would demonstrate the potential for parental influence on medical decision-making.[260]

In some cases, children with similarly dismal prognoses faced very different outcomes in the French and American units. Life-sustaining treatment was withdrawn from a child in a French unit whose parents had expressed a wish to see treatments pursued (the child died after nine days in the NICU) whereas treatments were continued in the same circumstances in the American Unit (the child was discharged after 78 days in

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[257] Orfali, *supra* note 115 at 2010.
[258] *Ibid.*
[259] *Ibid.* at 2011.
[260] *Ibid.* 2010.

the NICU). However, Orfali reports that things by no means consistently followed this expected pattern.[261] In the United States, parental autonomy is severely limited by two factors: a legal environment that denies parents the right to refuse medical treatment that is medically indicated, and parents' dependence on medical experience and authority to determine what is medically indicated and what is open for discussion. While French physicians do not ask parents' permission to withdraw treatment, American doctors do not consult parents before continuing. Orfali concludes that the marked difference in outcomes between American and French NICUs cannot be attributed to greater parental influence in an autonomy-based model.[262] Rather, she attributes the difference in outcomes to the fact that in spite of the different legal contexts, parents are equally likely to agree with the physician's recommended treatment or withdrawal plan. Accordingly, different outcomes for similar prognoses in France and the United States reflect different medical attitudes toward prematurity-related disability and morbidity rather than parental influence on medical decision-making.[263]

In both the French and American contexts, healthcare professionals manage to exclude parental participation by reconstructing ethical "gray zones" in a manner that confirms medical authority. In the NICU, ethical gray zones arise mainly around the axis of prognostication. When babies present to the NICU because of prematurity-related conditions, birth asphyxia or congenital malformations, physicians are not only asked to predict viability but also intellectual potential and quality of life.[264] In that light,

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[261] *Ibid.* at 2014.
[262] *Ibid.*
[263] *Ibid.*
[264] *Ibid.* at 2015.

predicting outcomes with certainty is as elusive as describing what is an acceptable quality of life. Yet, admitting that prognostic uncertainty, and consequently ethical uncertainty, is embedded in the medical decision-making process requires physicians to surrender their monopoly on expertise and accept outside intervention from parents, policy-makers, ethics consultants, spiritual advisers and other outsiders.[265] While cultural differences have an impact on the way in which ethical dilemmas are managed, the result of parental alienation is essentially the same. French neonatologists retain control over prognostic uncertainty by establishing “objective criteria” that become “internal rules and guidelines,” making all arguments of prognostication essentially medical, and blurring the lines between ethical and medical expertise.[266] American neonatologists rely heavily on what Anspach termed “perceptual and interactional cues” to assess how much an infant can hear, see or interact with her surroundings.[267] If an infant looks well despite a dismal prognosis, American neonatologists are unlikely to involve parents in their ethical reflection. So whereas French specialists manage uncertainty by turning it into medical certainty using a professional normative framework, American neonatologists hide behind the “veil of uncertainty” and continue treatments until all clinical observations point to a near and certain death.[268] Taking, as Orfali does, the example of a grade IV intra-ventricular hemorrhage (IVH)[269] diagnosed by ultrasound imagery in an infant who is moving well and starting to suck, French neonatologists would evacuate ethical reflection by relying on the ultrasound results whereas American neonatologists would do the same by relying on the child’s clinical behavior and the prognostic uncertainty of severe IVH.

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[265] *Ibid.*

[266] *Ibid.* at 2016.

[267] *Ibid.* at 2015.

[268] *Ibid.* at 2017.

[269] The most severe degree of brain hemorrhage, likely but not guaranteed to cause physical and intellectual developmental delays.

Either way, physicians control and limit which treatment options will be offered to parents.[270]

4.3 Concluding remarks

Critical legal pluralism enjoins us to look at law-creating interactions between subjects, and challenges common understandings of law as a hard substance (*dura lex sed lex*). Under the pluralist lens, law is able to adapt to social change since the interactions and expectations that bring about social change are the ones from which law emerges. When conceptualized as a flexible instrument, law can withstand social change without losing its substance.[271]

The image of law as concurrently transformed by society and transforming society opens a window into the sheltered world of the NICU by exposing the particular dynamic of interactions between parents and personnel as a heuristic enterprise. Formal law's reach into the decision-making process is not significant enough to touch decision-makers meaningfully, leaving them to find a common language to organize their interactional needs and expectations.[272] This language may exist within the "frame" of formal law but can also mold it, stretch it or occupy its periphery. Identifying the locus of internormativity per formal law can yield valuable insight on the transforming power of law or, if internormativity is challenging the substance of formal law, become a precursor of social change.

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[270] Orfali, *supra* note 115 at 2017.
[271] Belley, *supra* note 8 at 9.
[272] *Ibid.* at 10.

The internormative landscape highlighted by the empirical work of Anspach, Pinch, McHaffie, Payot and Orfali shows ethical decision-making as a process of engagement between health care professionals and parents. However, the same research shows that the expectations and standpoint of parents and health care professionals vary to such a degree as to make *shared* decision-making elusive. The assent model seemingly prevalent in NICU places parents at the periphery of ethical decision-making by determining what constitutes an area of ethical uncertainty on which their input should be sought. At this point in their child's medical course, parents are conscious of their dependence on the skills and knowledge of health care professionals and consumed by their own ethical dilemmas. Consequently, parents are not necessarily aware of the existence of ethical dilemmas among health care professionals and the consequences of these dilemmas on their family's life.

Recast in terms of legal pluralism and internormativity, I observe that internormativity in the NICU can be analyzed in different ways leading to complementary conclusions. First, normative interactions can be examined at the level of the legal subject as advocated by Kleinhans and MacDonald.[273] At this level, empirical research shows that while parents embrace their decision-making authority – apparently aligning their interactional expectations with Canadian law and medical practice guidelines – healthcare professionals in fact maintain a monopoly on the construction of ethical dilemmas and medical uncertainty. The primacy placed on the medical norm in the determination of a child's best interest and the imbalance of knowledge and experience between parents and health care professionals puts pressure on and tests the legal framework of shared

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[273] *Supra* note 4 at 38.

decision-making and forces each into a process of legal transformation. Parents renounce their share of medical decision-making in favor of health care professionals who reconstruct ethical dilemmas in terms of medical decision-making thus excluding -- in many instances -- extra-medical influences.

Secondly, internormativity can be examined at the convergence point of normative orders, where norms assimilate, ignore or antagonize each other.[274] The fabric of interactions knitted by parents and professionals in their effort to fill the space between enacted normativity and their reality eventually comes in contact with the boundaries of formal law and must reckon with its expectations. Informed consent must be obtained, parents must be consulted, and forms must be signed. Forecasting the contact point between self-created normativity and law “properly-so-called” creates a new realm of internormativity meant to preserve the appearance of shared decision-making, informed consent and various institutional policies like family-centered care or cultural pluralism.

Self-created normativity is not only transformed by formal law, it transforms it. The next chapter will reflect critically on the emergence of plural law in the neonatal context with a view to highlighting the implications of excluding the normative voice of parents from day-to-day medical decision-making concerning critically ill newborns.

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[274] Rocher in Belley (ed.), *supra* note 8 at 26-27.

Chapter 5: Standard of care as an internormative enterprise

In previous chapters, we saw that the legislative framework underlying surrogate decision-making fostered the expression of legal pluralism. However, we also saw that the application of the best interest test by Canadian courts and medical practice guidelines typically defined the best interest of the child strictly as "best medical interest." Subsequently, we observed that the strict definition of best interest according to medical norms created a practice whereby parental input was only sought in cases of medical uncertainty or neutrality, thus leaving an infant's physicians in control of the circumstances in which parents could participate in the shared decision-making process. This fifth and last chapter will reflect on the convergence of neonatal decision-making and legal pluralism by exploring the implications of excluding parental participation from the shared decision-making process for law's emergence and legitimacy in society.

Using the observations developed in the four previous chapters, I will argue that the limitation of parental agency in neonatal intensive care prevents the integration of family-based normativity into the law-making dynamics of the NICU. Starting from the premise that internormativity occurs at every level of human interaction and provides insight into the purpose and legitimacy of law, I will argue that parents engage in normative processes by conforming to or resisting the role they are given at the bedside. I will continue with a critical reflection on the role of conformity and resistance in the emergence of plural law using the example of mechanical ventilation and total parenteral nutrition to illustrate the consequences of excluding family-based normativity from the development of medical practice guidelines. Finally, I will argue that the characteristic prognostic uncertainty of critically ill infants calls for greater parental involvement in medical decision-making to ensure that formal law – embodied in statutes, judicial decisions or practice guidelines –reflects parental normativity adequately and legitimately.

5.1 Legal pluralism in the NICU: Normative interactions and formal law

Parents in NICU: Legal pluralism and the body analogy

By focusing on the legal subject's role in creating and transforming normative communities, critical legal pluralism uses the knowledge and imagination of those who produce legal interactions as the starting point for its analysis of law. Brought back to the analysis of decision-making in NICU, critical legal pluralism would highlight why and how the formal role of parents is transformed in the neonatal context. While it would be possible to end the analysis of decision-making in the NICU by concluding that the law is broken (because it does not reflect the needs and experience of some decision-makers) or that parent-physician interactions are broken (because they do not correspond to the image that formal law has of them), critical legal pluralism challenges us to think of the relational character of the decision-making process in NICU and the ways in which parents contribute to the creation of their own role in this process.

The legally plural dialogue between parents and physicians at the bedside does not stop when parental voices are excluded from ethically charged decision-making. The turn to critical legal pluralism reveals that dynamics of opposition or exclusion between normative orders also constitute normative interactions contributing to the emergence and legitimization of law in society.[275] By refusing to draw boundaries between normative orders and recognizing that legal subjects manipulate and transform the norms that affect them, critical legal pluralism questions what kind of norm-creating interactions emerge from the contact between parents, physicians and state-based legal institutions as sites of normativity sharing an intellectual space.[276]

To better illustrate the emergence of plural law in the midst of decision-making in NICU and to set these interactions in the context of critical legal pluralism, I will draw an organic[277] picture of decision-making whereby sites of normativity are conceived as organs, each forming a basic and inherent part of the body of law and existing together in organized efficiency. Parents, health care workers, formal law and medical guidelines co-exist, inform, and transform each other in a manner analogous to the interdependence between organs of the human body. In the human body, sickness in one organ often brings sickness in other organs. For instance, a back ache may develop when we limp for a period of time: by compensating for the bad knee, we create the bad back. The back's proper function in the walking motion depends on a balanced gait.[278] Similarly, when parental voices are denied the influence they are given by institutional law, they do not disappear altogether from the internormative landscape but start influencing it in dysfunctional ways. Returning to chapter 1 and Lon Fuller's observations on the "internal

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[275] See above p. 22 to 24.
[276] *Ibid.*
[277] Meant as "naturally and efficiently organized," Microsoft Encarta Dictionary, *s.v. organic.*
[278] The body analogy has limitations however. In the human body, the organized efficiency of the various systems is such that complete failure in one system can cause the death of the entire body (e.g. renal failure, myocardial infarction or ischemic brain injury). In human interactions, dysfunction in one system creates new or different interactions but does not bring about the death of plural law. In law, even the absence of interaction is a relational dynamic.

morality of law,"[279] points of resistance between parents and other normative orders may flag weaknesses in law's structure and direct us toward improving its internal morality, functionality and legitimacy. A critical insight into these points of resistance help us identify avenues of empirical enquiry looking into the strengths and weaknesses of our present system of surrogate decision-making and, eventually, into the development of better health law and health policy.

To analyze the interface between parent-based normativity and medical practice guidelines, I will argue that formal law makes allowances for the co-existence of plural normative interactions and functions with the assumption that legal subjects influence its make-up. From that perspective, parents "spin the filaments" [280] of the fabric of law by their exclusion, but in a manner comparable to the back ache caused by the uneven gait: functionality is maintained but inefficiently.

Normative influences and formal law: Resistance and conformity

In Chapter 2, we saw that formal Canadian law gives parents a privileged role in making decisions on behalf of their children.[281] In matters of surrogate decision-making, formal law sees parents as important influences in the decision-making process but the interaction of formal law with medicine-based normativity effectively shuts down all means of communication with parents as a normative order and formal, rule-based normativity. By assuming that parents are better placed to appreciate what constitutes their child's best interest, the law seems to recognize that best interest is an organic notion

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[279] Above pp. 14 and 26.

[280] Kleinhans & Macdonald, *supra* note 4 at 37.

[281] See above p. 42.

born of the factors making families distinct from one another. In appearance, the state's oversight of family life confirms a plural outlook: in every day life, parents are allowed to align the upbringing of their children with their values, priorities and aspirations. In fact, below a threshold showing evidence of abuse, parents are given wide latitude in the conduct of their family affairs, including decisions that effectively give precedence to family priorities over individual children's interest.[282] However, the threshold of state intervention in parental decisions changes when parents make medical decisions on behalf of their children. In the context of the everyday life of healthy children, parents possess extensive decisional latitude until their decisions threaten the life and integrity of their children. In the context of a treatment decision, even delay in making the right decision can threaten the life and integrity of the patient. Accordingly, parents entering the realm of medical decision-making face a much greater scrutiny than they do in the conduct of their non-medical family affairs. Parents react to this change in law's ambit by resisting or conforming to the limits put on their role as decision-makers and in doing so, partake in the emergence of plural law.

Resistance and conformity are two ways in which parents simultaneously define and are defined by their legal subjectivity. At a very basic level, resistance is born of the normative make-up of an individual: images of the self informed by culture, life experience, moral life and emotional response all contribute to shaping parents' reaction

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[282] Bala & Redfearn, *supra* note 89 at 279. See also *Children's Aid Soc'y of Winnipeg v. R.I.M.* (1980), 15 R.F.L. (2d) 185: "The right of a natural parent to the care and control of a child is basic. It is a right not easily displaced. Nothing less than cogent evidence of danger to the child's life or health is required before the court will deprive a parent of such care and control."

to their limited role in medical decision-making.[283] When parents resist the limits put on their decision-making authority by the medical context, their response affects legal subjectivity by stimulating individual and institutional responses to resistance. Health care workers, who may feel like their professional integrity and competence are in question, often react by avoiding or antagonizing parents even more. Interpersonal dynamics emerging from resistance are normative at their most basic level in that they directly impact the language of interactions believed to be the genesis of law from a pluralist perspective.[284] Resistance can also impact normativity at the institutional level by informing policy initiatives following a particularly painful episode of parental resistance or by affecting subtle attitude changes at the level of institutional culture.[285] As an example, the publication of Stinson & Stinson *The Long Dying of Baby Andrew*, [286] started as a personal letter from the authors to the hospital's administration requesting a review of the institution's truth-telling and informed consent policies. When the hospital failed to address their concerns meaningfully, Richard and Peggy Stinson sent a copy of the twenty-four page letter to *The Atlantic Monthly* where a reduced version was published in 1979 under the title "On the Death of a Baby."[287] In 1986, ten years after Andrew Stinson's birth, Guillemin and Holmstrom published their research on neonatal

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[283] By stating that parental role is "limited," I am not arguing that parental authority should be unlimited. But formal law does limit parental authority at a basic level to prevent or correct abusive situations or for social policy purposes. The point of this argument is not to demonstrate that limitations on parental authority are unjustified but to illustrate that resistance as a motor of normative interactions is born of a reaction to an opposing force. In physics, "resistance" involves something to resist against, to slow down, and this is how I view limits to parental authority.

[284] On law as a language of expectations, see generally Fuller "Human Interaction and the Law," *supra* note 24.

[285] Rocher, *supra* note 7.

[286] *Supra* note The case of Andrew Stinson galvanized family and newborns' advocates and its impact on neonatal policy is un-researched but presumably important. See e.g Harrison, *supra* note 151 at 168; see also Guillemin & Holmstrom, *supra* note 114 at 141, 175, 245, 278; Lantos "The Lazarus Case" *supra* note 128 at 159-160.

[287] Richard Stinson & Peggy Stinson, "On the Death of a Baby" (1979) July The Atlantic Monthly 64-72.

intensive care[288] writing: "Hospital F was the scene of the Stinson and Stinson case which, though the institution was not identified, made the n.i.c.u. staff here acutely aware of the risks of poor communication with parents. [Reference omitted]." [289] Guillemin and Holmstrom's observation points toward the lasting effects of a painful episode of parental resistance, both on NICU staff and on the emergence of hospital policy.

The effects of parental resistance can be amplified[290] to reach the spheres of formal law and health policy when it is countered by a court challenge resulting in a judicial pronouncement. At this point, resistance defines legal subjectivity not only for the family who will be submitted to the word of the tribunal but also for the families who will follow them at the bedside of a critically ill infant. At the health policy level, resistance and the ensuing institutional debate can lead to a policy response, for instance when the application of formal law by the courts leads to an injustice or to a scandalous outcome in the public eye. Such was the case when the Baby Doe regulations were adopted. The death of a child with Trisomy 21 whose duodenal artresia was not corrected caused a sense of outrage that elicited a policy response from the government in power.[291]

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[288] Guillemin & Holmstrom, *supra* note 114.

[289] *Ibid.* at 245.

[290] In this context, I use the word "amplified" according to its electronics' definition, meaning "to increase the magnitude of a signal," Microsoft Word, Encarta dictionary *s.v.* "amplify." I do not suggest that resistance becomes stronger or greater once it is added to the body of formal law, but rather that formalization makes a private internormative encounter audible to society in general.

[291] See Robertson, *supra* note 197. Many argue that the Baby Doe regulations were an over-reaction, see e.g. Loretta Kopelman, "Are the 21-Year-Old Baby Doe Rules Misunderstood or Mistaken?" (2005) 115 Pediatrics 797. In a presentation given at McGill's Biomedical Ethics Unit on January 23rd 2008, Dr. Joel Frader, MD, (Professor of pediatrics and Professor of medical humanities and bioethics at Northwestern University, head of general academic pediatrics and associate director of The Bridges Program - Pediatric Palliative and End-of-Life Care at Children's Memorial Hospital in Chicago, Illinois), declared the Baby Doe Rules irrelevant and unhelpful for healthcare professionals facing difficult ethical dilemmas involving the care of critically ill infants.

Internormativity does not only include phenomena whereby norms are integrated from one normative order into another – as is the case when a normative stance is confirmed or denied through a judicial process – but also the dynamics of contacts between normative categories, orders or systems.[292] If resistance challenged by health care professionals and formalized by the courts has an observable impact on the emergence of law, conformity spins the internormative fabric of law more subtly but as significantly.

We saw previously that law was too blunt an instrument to address meaningfully some of the more delicate aspects of human experience.[293] Accordingly, if surrogate decision-making can be conceptualized on a continuum, I argue that there is a significant variation between the full exercise of surrogate authority and the point where this authority has been illegally denied. Subtle influences on free and informed choice can undermine surrogate decision-making without removing it completely. The point of impact of parental conformity and decision-making practices in NICU is an integral component of the gradation of surrogate decision-making from free and unqualified to effectively meaningless. At the institutional level, conformity informs which practices are acceptable to parents and which ones cause resistance.[294] Patterns of conformity also inform the point at which parental behavior is perceived as resistant. For instance, in an institution where parents are asked to leave the bedside during medical rounds,[295] parents

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[292] Rocher, *supra* note 7 at 28.

[293] Above, p. 96-98; See generally: Fuller "Law's Precarious Hold on Life," *supra* note 73.

[294] The emphasis is on "pattern" rather than "normative interactions." On an individual basis, what is acceptable to one family might not be for another one. But some practices will be generally accepted whereas others will be generally opposed.

[295] Medical rounds are the act of seeing patients one by one in the hospital setting. In teaching hospitals, rounds are an essential component of medical education. Patients' cases are discussed at the bedside by

requesting to take part in discussions concerning their child might be labeled as resistant even if parental attendance during rounds is the norm in another institution (or another floor in the same institution). As such, conformity has an important role in defining defiance and power relations in an institutional as well as interpersonal setting and takes the same path as resistance toward formalization or codification.

This pattern of conformity and defiance as the genesis of normative interactions is problematic in the medically uncertain field of neonatology. The arbitration of uncertainty in neonatal intensive care is a normative process where uncertain outcomes are balanced in light of desirable goals. The choice of a desirable goal and the management of uncertainty in the manner most likely to reach that goal are both infused with the normative make-up – values, education, ethics etc. – of those involved in the decision. Because the management of uncertainty involves a value-laden decision about preferred outcomes, medical and ethical uncertainty should be the object of a substantial normative dialogue between parents and health care professionals. When treatment or non-treatment decisions are marred by medical or ethical uncertainty, families should hold the balance of power in the decision-making process. Based on this position, the next section will analyze features of neonatal intensive care that militate in favor of giving parents the balance of power when making ethically charged decisions.

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health care professionals and students. In some institutions, psycho-social rounds, mortality rounds and pediatric palliative care rounds are discussed behind closed doors among health care professionals.

5.3 The neonatal context and legal pluralism: Managing uncertainty

In neonatology, medical innovation has followed the usual pattern of scientific exploration but with some accommodations. Most disciplines of medical science were developed through the articulation of questions followed by the elaboration of hypotheses born of observations and their validation through research. However, the pace of technological innovation in neonatology has seen the introduction of treatments before randomized trials and research protocols could confirm their efficacy.[296] The field of neonatology has eluded the habitual sequence of question, observation, hypothesis and testing in favour of "experimental leapfrogging"[297] whereby innovation is born of the retrospective observation of results from which hypothesis are singled out and tested. Unfortunately, once usage makes innovative or experimental medical interventions standard for the treatment of critically ill newborns, it binds health care professionals involved in their care. In this context, the characteristic uncertainty of neonatal medicine permeates every decision.

The following sub-sections consider why parents should hold the balance of power in neonatal intensive care. I will argue first that ethical dilemmas are not a private matter. Their occurrence in institutional settings wields an impact on other decisions in the NICU and has the potential to affect other parents of critically ill infants. Secondly, I will argue that parents should have more influence in determining reasonable medical care for critically ill newborns since accepted medical practices born of usage bind

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[296] Lantos & Meadows, "Neonatal Bioethics" *supra* note 131 at 2.
[297] *Ibid*. at 29.

physicians. I will illustrate that point using the development of two neonatal therapies: mechanical ventilation and total parenteral nutrition. Finally, I will conclude with a reflection on parental input in the establishment of the medical practice guidelines that frame the medical care of imperilled newborns.

Ethical dilemmas are not private matters

Legal pluralism draws attention to the interactive nature of law. Re-enlisting the help of the body analogy discussed above, law as a system is only as organized and efficient as the sum of its parts.[298] Dysfunction in the balance of normative influences or in the ideology underpinning the edifice of law do not destroy law but affect changes in its interpretation, application and efficiency as a means of social ordering. It follows that if changes in one normative order can bring about changes in the whole structure, decisions surrounding complex ethical dilemmas wield an impact on other decisions made in NICU. The idea that decisions about ethical issues take place in the context of institutions, organizations and power relationships is not exclusive to legal pluralism and in fact, constitutes the cornerstone of Renée Anspach's sociological study of life and death decisions in the NICU.[299]

The existence of ethical dilemmas and the following decisions are informed by several layers of normative influences and have a ripple effect over many normative orders, from parents and health care professionals to administrators and policy-makers. There is a case to be made for the importance of including the voices of each stakeholder

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[298] See above p. 101-102.
[299] Anspach, *supra* note 69 at 21 and 165.

into the moral reflection that leads to controversial treatment decisions, especially when these treatment decisions are essential to the creation of formal, widely applicable, law.[300] This not to argue that a democratic vote should preside over every controversial decision, but if we consider that society at large has a voice in the rank-ordering of funding priorities in health care and that administrators allocate health care resources at the institutional level, we can see that the immediate neonatal environment in which parents and health care workers operate is already infused with competing normative influences.

Standardization binds physicians

Once a treatment or course of treatment becomes a standard of practice, physicians are legally required to provide it. Failure to do so may bring about a finding of professional negligence and the correlating obligation to compensate the victim of that negligence for her losses.[301]The point of crystallization of medical practices into formal law effectively removes any flexibility parents may have had in requesting unconventional treatment or refusing treatment deemed *normal*. However, the process of judicial standardization only allows the recipients of medical services to voice their concerns inasmuch as they are legally significant for the particulars of their case. The process of standardization considers ethical disagreements when they are voiced by competing medical testimonies. Yet parents who feel wronged by broader issues of medical culture do not have a formal forum in which to express themselves unless they

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[301] The concept of "approved practice" offers the physician who acted "in accordance with a recognized and respectable practice of the profession" a means of defense against a negligence claim. *Ter Neuzen v. Korn,* (1995) 127 D.L.R. (4th) 577 (S.C.C.); [1995] S.C.J. No. 79; [1995] 3 S.C.R. 674 (Q.L.) at para. 33. However, when standards of practice are not reasonable in caring properly for a patient physicians may be held to a higher standard than the standard set by the approved practices. See *Ter Neuzen v. Korn*, see also *Roberge v. Bolduc*, [1991] 1 S.C.R. 374, [1991] S.C.J. No. 15 (professional liability of notaries public).

have been wronged in a manner that the courts can grasp.[302] When parties seek a judicial pronouncement on standard of care, they expect an answer. The courts' role is not to weigh in on the course of medical research but to declare, at a given point in time, what the standard of care is in a given situation. The judicial process of standardization highlights the importance of allowing parents to incorporate their normative make-up – expressed as resistance or compliance – into treatment decisions before they are embodied in formal law.

Normalizing uncertainty: The case of mechanical ventilation and TPN

The crystallization of standard practices with their residual or inherent ethical uncertainty is particularly problematic in neonatal intensive care where many medical interventions have never outgrown the initial uneasiness that accompanied their introduction into neonatal care. Two examples of treatments illustrating this difficult dichotomy are prolonged mechanical ventilation (more than 28 days) and total parenteral nutrition (TPN)[303]. In *Neonatal Bioethics,* Lantos and Meadow conduct a review of the development by trial and error of mechanical ventilation and TPN.[304] They posit that the

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[302] To get a sense of the frustration of parents who are looking for a forum in which to express their negative experiences with neonatal care, see Stinson & Stinson, *supra* note 162. For a shorter but equally poignant account, see Nancy Montalvo & Brian P. Vila, "Parents Grand Rounds Speech on Neonatal Intensive Care Unit Experience" (1999) 19 (7) Journal of Perinatology 525. Nancy Montalvo and Brian P. Vila sued the physician who resuscitated their prematurely born son (23 weeks). The authors alleged that the physician's failure to obtain informed consent amounted to medical negligence. Their case was denied in first instance and in appeal on the grounds that they did not have the authority to refuse life-saving treatment for their son, making the informed consent unnecessary: *Montalvo v. Borkovec* (2002) 256 Wis.2d 472, 647 N.W.2d 413.Wis.App.

[303] Total parenteral nutrition is also known as intravenous feeding. It provides patients with fluids and nutrients when they are unable to feed by mouth.

[304] Lantos & Meadow, *supra* note 131, generally. Mechanical ventilation uses a mechanical device to deliver air into the lungs of patients whose respiratory abilities are diminished or lost. Because their lungs are still undeveloped, premature infants usually need respiratory assistance in their first weeks of life. Complications of prolonged mechanical ventilation include brochopulmonary dysplasia (BPD) or scarring of the lung tissue making the absorption of oxygen by the body difficult or impossible. BPD is a chronic

initial development of mechanical ventilation and TPN occurred at breakneck speed in the sixties and seventies. As with many medical innovations, mechanical ventilation and TPN were developed to solve specific problems in neonatology but did not pay significant attention to the new problems they were creating.

Mechanical ventilation and nutritional support caused ethically complex situations at two levels. At the immediate level of ethical reflection, the side effects and complications of mechanical ventilation and TPN had to be weighed against their benefits. But the life-saving nature of both interventions made it morally difficult to halt their development while stakeholders debated whether impaired life could fairly be weighed against no life. The second level of ethical reflection involved whether all lives were worth saving. Quality of life judgments aside, there is only so much viability medical science can infuse into infants who should have remained *in utero* for another four months. Some children hang to a medically sustained life for many weeks before letting go.[305] The difficulty of predicting with accuracy which children will benefit from aggressive life-saving treatment and which children will be severely impaired by its use has forced policy-makers to choose between treating all children at the risk of salvaging lives of suffering, or denying treatment to all children at the expense of those who would

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condition. Total parenteral nutrition is the practice of feeding patients intravenously using nutritional formulas. In neonatology, TPN is used to provide adequate nutrition to newborns who cannot absorb nutriments through the gastro-intestinal tract. Complications of TPN include line-based complications such as infections, and metabolic complications such as hyperglycaemia (high blood sugar), hyperlipidaemia (high level of fat in the blood) and cholestasis (a symptom of liver disease). This information was gathered informally during my placements at the Montreal Children's Hospital (winter 2007) and the Children's Hospital of Eastern Ontario (summer/fall 2007) and is provided as background information only.

[305] Such was the case of Andrew Stinson, see generally Stinson & Stinson, "The Long Dying of Baby Andrew" *supra* note 162.

have survived.[306] Choosing the former, mechanical ventilation and TPN gradually became standard treatment for extremely premature infants. There is no jurisprudence in Canadian law discussing the provision of mechanical ventilation or TPN as standard of care for newborns, but the CPS/SOGC Guidelines[307] recommend that "any required neonatal treatment" be provided to infants born after the 25 week mark, thus suggesting that the failure to provide mechanical ventilation or TPN would probably fall below the accepted neonatal standard of care.[308]

Returning to Canadian medical guidelines, the legal pluralism and normative underpinnings of providing neonatal therapy to children born after 25 weeks and denying it to children born before completing 22 weeks of gestation are situated in the myriad normative decisions involved in issuing a clinical guideline.[309] The purpose of this argument is not to discuss whether the guidelines are ethically acceptable but rather to highlight the internormative process of deciding where the buck stops (or, for some neonates, where it starts). For instance, when the Fetus and Newborn Committee states

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[306] Medical research in neonatology is constantly trying to improve its ability to predict the outcomes of extremely premature infants before life-sustaining treatment is initiated, recognizing that it is always easier to withhold treatment from children who won't benefit from it than to withdraw it once it is deemed futile. Examples of such research can be found in William Meadow *et al.* "Serial Assessment of Mortality in the Neonatal Intensive Care Unit by Algorithm and Intuition: Certainty, Uncertainty, and Informed Consent" (2002) 109 (5) Pediatrics 878; and in Annie Janvier & Keith J. Barrington, *supra* note 167. For discussions on the unreliability of viability determinations based on birth weight or gestational age, see Lantos Meadow, *supra* note 131 at 85-111; for a discussion of the dangers of using strict guidelines for the determination of viability, see Annie Janvier & Keith Barrington, "Advocating for the Very Preterm Infant" (2006) 118 Pediatrics 429 (the authors' daughter Violet would not have been offered treatment under strict gestational age or weight-based guidelines). For an example of self-imposed treatment guidelines, see Andrew Whitelaw & Victor Y. H. Yu, "Ethics of Selective Non-Treatment in Extremely Tiny Babies" (1996) 1 Seminars in Neonatology 297.

[307] *Supra* note 130.

[308] The CPS/SOGC Guidelines do not have force of law but do have an influence in the determination of approved practices. For a reflection on the integration of professional guidelines into case law, see Angela Campbell & Kathleen Glass, "The Legal Status of Clinical and Ethics Policies, Codes, and Guidelines in Medical Practice and Research" (2001) 46 McGill L.J. 473.

[309] Above at 63.

that children born before 22 completed weeks “are not viable”[310] it means that survival is such a rare occurrence, and major disabilities are so widespread, that neonatal medicine chooses not to treat these infants aggressively.[311] However, anecdotal evidence of survival suggests that some of these infants could benefit from neonatal therapy. The choice to declare these infants non-viable is influenced by normative pronouncements of the medical order observing that the intact survival rate is so low as to be virtually inexistent.[312] The consensus informing what constitutes an acceptable likelihood of intact survival may be based on the studied preferences of health care personnel, parents and lay people[313] but it also means that some families will request – and be denied – treatment for their premature infant. [314] Conversely, parents who believe that 25 weeks does not represent an acceptable level of intact survival will not be allowed to withhold treatment from their premature infant. If at first glance gestational thresholds of treatment are created to determine which babies will be treated and how aggressively, the normative factors underpinning these thresholds expose many layers of societal perceptions and expectations relative to the potential of neonatal intensive care patients. The decision to treat or to withhold treatment from children who threaten to develop severe cognitive of physical disabilities reveals to what extent we are willing, as a society or as individuals, to accept and support life even when it comes with severe limitations. It forces us down a

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[310] CPS/SOGC Statement, *supra* note 130 at 591.

[312] A table of study results on survival reporting rare occurrences of survival for infants born before 23 weeks gestation, see M. Hack & A.A. Fanaroff, “Outcomes of children of extremely low birth weight and gestational age in the 1990s” (2000) 5 Seminars in Perinatology 89.

[313] Naveed Hussain & Ted S. Rosenkrantz, ““Ethical Considerations in the Management of Infants Born at Extremely Low Gestational Age” (2003) 27 (6) Seminars in Perinatology 458 at 463.

[314] See *supra*, note 153: Mother lying about her gestational age upon admission to secure neonatal therapy for her infant daughter, later born at 21 weeks gestation. The infant survived and was discharged home after spending 4 months in hospital. In their article Hussain and Rosenkrantz attribute occasional survivors to “biological variation or inconsistency of pregnancy dates.” Hussain & Rosenkrantz, *ibid.* at 459.

difficult path of questioning the relative importance of physical and cognitive ability, as well as our willingness to integrate disability into the fabric of our particular families and of society in general. A detailed foray into these normative influences is beyond the scope of this thesis but the existence of such influences points toward several potential avenues of empirical enquiry. Important conclusions could be drawn from empirical observations on the level of treatment granted to premature infants versus infants born with congenital malformation or brain injury.

Concluding remarks: The importance of parental voices

While approved practices cannot be established on an *ad hoc* basis, we must recognize that clinical practice guidelines are not normatively neutral. They are informed by medical culture, impact medical practice, and have long-lasting consequences on the lives of the families they affect. Based on the review of Canadian clinical guidelines on shared decision-making conducted in chapter 2 and the empirical research on parental experience analyzed in chapter 3, I posit that the internormative process whereby thresholds of meaningful viability were established did not include significant parental input. The normative process whereby ethical uncertainty is processed into medical certainty has had the result of removing the possibility of parental resistance to ethically problematic treatment avenues. Making resistance impossible has curtailed an important dimension of parental influence and has challenged the integration of parental normativity into formal law embodied in standard of care or the best interest standard.

5.4 Conclusion

In chapter 5, I observed that clinical practice guidelines were normative pronouncements. The exclusion of parents from the shared decision-making model has the effect of preventing parent-based normative influences from factoring into law-making dynamics in NICU. The state of decision-making in neonatal intensive care is particularly problematic in light of the difficulty of making accurate prognoses and the inherent ethical uncertainty of therapeutic standards in neonatology. Because of their binding nature on physicians, standardized treatments and conceptions of best interest can be tremendously emotionally, physically and financially onerous on families. Fairness and legitimacy demand that ethical uncertainty in the treatment of critically ill newborns be arbitrated by parents to ensure their participation in the normative make-up of law in the NICU.

Conclusion

Critical legal pluralism's contribution to the study of the shared decision-making process in neonatal intensive care shows us that formal law's approach to surrogate decision-making neglects the impact of normative influences on the outcome of a medical decision. The clear definition of roles and responsibilities suggested by formal legal and medical guidelines does not reflect the lived experience of parents and health care professionals gathered at a critically ill infant's bedside. While formal law suggests a model where parents make medical decisions on behalf of their child, medical practice guidelines respond by an adaptation of the formal model recognizing the interdependence between physicians and parents engaged in the decision-making process. But the transformation of law does not stop at the accommodation of formal law by medical practice guidelines. The tendency of Canadian Courts and medical authorities to limit the best interest of a child to her best *medical* interest has caused a transformation of the shared decision-making model meant to preserve medical authority in the determination of a child's best interest. As a result, parental input is not sought meaningfully if the best interest of a child has already been ascertained according to medical determinants such as statistical outcomes, likelihood of recovery and side-effects of treatment. Recast in terms of critical legal pluralism, this accomodation of formal rules of surrogate decision-making to the context of the NICU emphasizes medical normativity while effectively muting normative influences on parental decision-making.

The predominance given to medical normativity in the shared decision-making process seems to contradict the tenets of Canadian formal law acknowledging parents' privileged position to appreciate what constitutes their child's best interest. The transformation of formal law into a modified model of surrogate decision-making is particularly problematic in the medically uncertain field of neonatal intensive care. Where most treatment decisions involve an element of ethical uncertainty, the emphasis on medical normativity leads health care professionals to prevent the involvement of parents in the arbitration of ethical uncertainty by reformulating ethical uncertainty in medical terms thereby turning it into a medical matter. The normative process seeing ethical uncertainty expressed in terms of medical certainty has important implications for informed consent in surrogate decision-making and causes another transformation of formal law. Because best medical interest is within the purview of the medical profession and failure to act in the best interest of the child will trigger institutional scrutiny – and possibly the state's *parens patriae* jurisdiction – into the surrogate decision-making process, health care professionals have taken to determining what constitutes the child's best interest and seek parental *assent* to the preferred course or treatment rather than inform parents about a range of treatment options to which they must consent. The assent model in neonatal intensive care has been widely reported in empirical studies on parental experiences of neonatal intensive care which are reviewed in this thesis.[315]

The process whereby formal law is created, transformed, and adapted by individual normativity is at the root of critical legal pluralism.[316] When health care

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[316] Kleinhans & Macdonald, *supra* note 4 at 38.

professionals and parents, by their interactions, restrict the scope of surrogate decision-making to effectively remove parental normative input from decisions made on behalf of their children, they illustrate the premise of critical legal pluralism. The pluralist definition of law is not limited to its formal state-based expression – in rules, regulations and court decisions – but extends to norms that direct human behavior toward a desired end. This thesis sought to demonstrate the disconnect between formal rules of surrogate decision-making and the way in which these rules are applied and lived in neonatal intensive care. Using the window opened by legal pluralism into neonatal intensive care, this thesis is but a stepping stone into an array of questions which should eventually be the object of further research. A clear picture of the normative environment of Canadian NICUs is paramount to the conception of sound health policy, legal reforms into surrogate decision-making and best interest standards. The next step would be to find innovative ways to integrate parent-based normativity more truly into the process of establishing the medical practice guidelines that wield an impact on parental experience in the NICU.

As the cornerstone of this thesis is the parents or critically ill newborns, it seems fitting that they should be given the last word. In an article recently published in the journal Paediatrics & Child Health, my friend Barbara Farlow relates the events surrounding the death of her daughter Annie and her pain at discovering later that she had been denied input in treatment decisions:

> “The Coroner and his committee noted issues about our daughter’s final admission. An effective “Do Not Resuscitate” Order had been placed on her chart, yet this had not been discussed with us. There are no words to describe

> the pain we felt when we discovered that our rights as Annie's parents to provide input into critical decision making had been overlooked.
>
> The infant with predicted disabilities lives the most fragile of human lives. The fate of our child rested in the hands of the physicians and health care providers. Unilateral treatment decisions and the absence of our input into or awareness of these decisions caused a double tragedy. We were denied both a chance to prolong Annie's life and a plan for her to die a dignified and peaceful death with her loving family surrounding her."[317]

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[317] Barbara Farlow, "The Decision to Accept Disability: The Experience and Perspective of One Family," (2008) 13 (5) Paediatrics & Child Health 367.

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