The duty to treat very defective neonates as "persons":

From the legal and moral personhood of very defective neonates to their best interests in medical treatment

By

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August 2003

A thesis submitted to McGill University in partial fulfillment of the requirements of the degree of LL.M. (Master's Specialization in Bioethics)

Your file Votre référence
ISBN: 0-612-98794-9
Our file Notre référence
ISBN: 0-612-98794-9

Abstract

The dramatic improvement of neonatal intensive care has produced vexing ethical and legal questions. One of the most striking issues is to determine whether the most defective neonates should be provided with intensive care and to what extent they should be treated. This thesis demonstrates that an attempt to answer this question and an analysis of the demands and limitations of a duty to treat defective neonates cannot properly occur without first considering the legal concerns and ethical issues surrounding the notion of "person". The author examines germane ethical theories and North-American jurisprudence to see what approaches and standards commentators and courts have adopted in this respect. This thesis demonstrates that in the context of the cessation or non-initiation of intensive care, the legal and moral status of very defective neonates remain ambiguous. In particular, the author suggests that a legal best interests analysis that includes quality of life considerations may actually involve the use of criteria similar to those supported by the authors of the controversial moral theories that negate the personhood of seriously handicapped newborns. The author ultimately concludes that a clear divide between the legal definition of the "person" and the moral and social perceptions of that term is misleading.

Résumé

Les progrès considérables réalisés dans le cadre des soins intensifs octroyés aux nouveaux-nés gravement atteints dans leur santé provoquent aujourd'hui de difficiles questions éthiques et légales. L'un des problèmes les plus délicats est de déterminer si et jusqu'à quel point les nouveaux-nés les plus atteints doivent être agressivement traités. Cette thèse démontre que pour tenter de répondre à cette question et analyser les contours et les limites d'une obligation de traiter médicalement ces nouveaux-nés, il est nécessaire et inévitable de s'arrêter en premier lieu sur le concept de « personne ». L'auteur passe en revue les différentes théories éthiques élaborées sur ce concept ainsi que les standards et approches adoptés par les tribunaux nord-américains à cet égard. Cette analyse démontre que, pour diverses raisons, le statut moral et légal du nouveau-né gravement malade ou handicapé est ambigu lorsqu'il s'agit de prendre des décisions médicales en son nom. En particulier, l'auteur suggère qu'une analyse légale des meilleurs intérêts de l'enfant qui inclut des considérations liées à sa qualité de vie peut nous conduire à prendre en compte les mêmes critères que ceux utilisés par certains auteurs controversés pour nier la personnalité morale des nouveaux-nés gravement handicapés. Dans ce contexte, l'auteur conclut que l'idée selon laquelle il existe une séparation claire entre le concept de personnalité juridique et les perceptions morales et sociales associées à la notion de « personne » est trompeuse.

ACKNOWLEDGEMENTS

I am grateful to Dr. Keith J. Barrington, and to all the staff of the Neonatal Intensive Care Unit at Royal Victoria Hospital, Montreal, for sharing their medical expertise, and also their doubts, hopes, and ethical concerns. I thank them for providing me with a remarkably supportive atmosphere and ongoing intellectual exchange about the ethical issues involved in neonatology.

I would like to express my deep gratitude to Megan Bowman. Writing this thesis in English was a great challenge to me and it would not have been possible without her. Moreover, this thesis has benefited from her insightful comments, suggestions and criticisms. Her strength, her talent, her vision of life, and her empathy not only enlightened my work but also every day in Montreal. I thank her for just being and wish her good luck in New York City.

I am indebted to Kathleen C. Glass, Director of the Biomedical Ethics Unit and Associate Professor at the Department of Human Genetics and Pediatrics, McGill University, Montreal, for her advice and review of this thesis and also for her continuous support and guidance throughout my studies at McGill University. In particular, I am grateful for the trust she has placed on me.

I acknowledge Professor Olivier Guillod, Director of the Institut de Droit de la Santé (IDS), Neuchâtel, Switzerland, the Foundation Louis-Jeantet de médecine, Geneva, and Me Pierre Gabus, for their help and financial support. Without doubt, my stay at the Foundation Louis-Jeantet has been a determinant step in my life. In this respect, I thank all its members and staff, and in particular the members of the Committee for the organisation of the National Louis-Jeantet Forums.

My greatest gratitude is to all my friends and my family. Alain, Ariane(s), Blaise, Camille, Claudine, Elsbeth, Eric, Gilles, Gramy, Guy, Irene, Jay, Jean-Patrice, Luc, Marianne, Michal, Natan, Olivier, Roxane, Sandra (Que ferais-je sans toi? Merci!), Sioban, Sylvie, Théo, Thibaud, Thierry, Tica, Tina, Yaël, Yoram et, bien sûr, Benoît: merci pour votre patience et vos encouragements incessants. Sans vous, rien de tout cela n'aurait été possible.

And without doubt, my deepest respect go to the neonates and to their parents. May their lives be full of hope and love.

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I. Introduction

Medical care for premature and very low birth weight infants (VLBW)[1] has dramatically changed and improved during the last two decades in all developed nations.[2]

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[1] A preterm delivery is one that occurs at less than 37 weeks of gestation and more than 20 weeks' gestational age: R.L. Goldenberg, "The Management of Preterm Labor" (2002) 100(5) Obstetrics & Gynecology 1020 at 1020 and World Health Organisation, *Basic newborn resuscitation: A practical guide* (WHO/RHT/MSM/98.1,1998): http://www.who.int/reproductive-health/publications/MSM_98_1/MSM_98_1_table_of_contents.en.html (accessed August 2003) at Chapter 8: "Glossary". Very low birth weight infants [hereinafter: "VLBW infants"] and extremely low birth weight infants [hereinafter: "ELBW infants"] are infants born with a weight inferior to 1500g and 1000g respectively: B. Westrup *et al.*, "Neonatal individualized care in practice: a Swedish experience" (2002) 7 Semin Neonatol 447 at 447; P.J. Van Reempts and K.J. Van Acker, "Ethical Aspects of cardiopulmonary resuscitation: where do we stand?" (2001) 51 Resuscitation 225 at 225.

[2] This statement has been made in most western publications and guidelines related to this topic. See for example: J. Cifuentes *et al.*, "Mortality in Low Birth Weight Infants According to Level of Neonatal Care at Hospital of Birth" (2002) 109(5) Pediatrics 745; J.D. Horbar *et al.*, "Trends in Mortality and Morbidity for Very Low Birth Weight Infants, 1991-1999" (2002) 110(1) Pediatrics 143; S.K. Lee *et al.*, "Variations in Practice and Outcome in the Canadian NICU Network: 1996-1997" (2000) 106(5) Pediatrics 1070. Specifically, great improvements have been noted in nutrition supports, in neuroimaging, in the techniques of resuscitation, in the management of respiratory failure and mechanical ventilation. See for example: S. Suri *et al.*, "Early Postoperative Feeding and Outcome in Neonates" (2002) 18(5) Nutrition 380; S.M. Donn and S.K. Sinha, "Newer techniques of mechanical ventilation: an overview" (2002) 7 Semin Neonatol 401; S.J. Counsell and M.A. Rutherford, "Magnetic resonance imaging of the newborn brain" (2002) 12 Current Paediatrics 401; C.M. Wong and B.J. Stenson, "Resuscitation of the preterm neonate" (2001) 11 Current Paediatrics 172; K.D. Rosenberg *et al.*, "The Effect of Surfactant on Birthweight-Specific Neonatal Mortality Rate, New York City" (2001) 11(5) Ann Epidemiol 337. Finally, one must underline that the situation is quite different in developing countries, where technical and financial means are limited. See for example: O. Ndiaye *et al.*, "Morbidité et mortalité néonatales au centre hospitalier Abass Ndao de Dakar (Sénégal)" (2001) 8 Arch Pédiatr 1019.

Thus, the development of high risk obstetric care[3], neonatal intensive care and a better access to these services[4] has affected the mortality of these infants.[5] Neonatologists are now able to save many infants who, in previous times, would not or could not have been resuscitated because of presumed lack of viability or merely because of the absence of effective technical means.

It is less clear, however, what global impact this evolution has had on the prevalence of children surviving with disabilities[6]. Studies have shown that a decrease in long-term sequelae has yet to be clearly demonstrated.[7] Indeed, while survival rates have improved, it seems that the incidence of most major morbidities remain unchanged,

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[3] See D.K. Richardson *et al.*, "Declining Severity Adjusted Mortality: Evidence of Improving Neonatal Intensive Care" (1998) 102(4) Pediatrics 893.

[4] R.L. Goldenberg, *supra* note 1 at 1020.

[5] Prematurity and VLBW remain the main causes of neonatal mortality, accounting for 60-80% of deaths of infants without congenital anomalies. Neonatal survival has progressed with over 50% of neonates surviving at 24-25 weeks of gestation, and over 90% surviving by 28 to 29 weeks of gestation: see for example R.L. Goldenberg, *supra* note 1 at 1020; V. Tommiska *et al.*, "A National Short-Term Follow-Up Study of Extremely Low Birth Weight Infants Born in Finland in 1996-1997", (2001), 107(1) Pediatrics: http://www.pediatrics.org/cgi/content/full/107/1/e2 at e2 (accessed March 2003); V. Tommiska *et al.*, "A national two year follow up study of extremely low birthweight infants born in 1996-1997" (2003) 88(1) Arch. Dis. Child. Fetal Neonatal Ed F29. In the United States, survival rates of 20-30% have been reported in newborns delivered at 22-23 weeks of gestation: M. Hack and A.A. Fanaroff, "Outcomes of children of extremely low birthweight and gestational age in the 1990s" (1999) 53 Early Hum Dev 193. The survival of VLBW infants was reported to be 70-75% in the late 1980s and has increased to over 85%: B. Westrup *et al.*, *supra* note 1 at 447. It has to be noted that a recent Canadian study has stressed the limitations of prior studies related to neonatal survival rates. The same study demonstrates an average survival rate of 56.1% for infants born at 24 weeks and 68% for infants born at 25 weeks: S.B. Effer *et al.*, "Neonatal survival rates in 860 live births at 24 and 25 weeks gestational age. A Canadian multicentre study" (2002) 109(7) BJOG 740.

[6] Potential long-term morbidities associated with prematurity and very low birth weight notably include cerebral palsy, mental retardation, retinopathy of prematurity, chronic lung disease and hearing loss. See for example: R.L. Goldenberg, *supra* note 1 at 1020; C.M. Wong and B.J. Stenson, *supra* note 2; P. J. Yoon *et al.*, "The need for long-term audiologic follow-up of neonatal intensive care unit (NICU) graduates" (2003) 00 International Journal of Pediatric Otorhinolaryngology 1.

[7] See for example Westrup *et al.*, *supra* note 1 at 447, and Horbar *et al.*, *supra* note 2 at 143.

which means that, in absolute numbers, the rate of surviving babies with disabilities has actually increased.[8]

In any case, one has to recognise that while new therapies have led to continued improvements in survival of premature and VLBW newborns, they are also frequently accompanied by neurologic or other disorders that previously would not have had time to evolve in the past or that can be associated with the life-saving intensive care provided to these infants.[9] Furthermore, the current organisation and technology for neonatal care improves the likelihood of treatment or may at least extend the period of survival of infants who are affected from birth with severe diseases, congenital malformations and/or multiple handicaps. Newborns may suffer from severe physical and/or mental anomalies which are not or not only related to their prematurity. For instance, babies born (prematurely or not) with a tragic and uniformly lethal condition such as Trisomy 13, Trisomy 18 or anencephaly may today be kept alive longer.

Moreover, neonates affected with other severe diseases (e.g. spina bifida, congenital diaphragmatic hernia, short gut syndrome, etc.) which involve multiple medical problems and controversial long-term quality of life, may be aggressively treated

[8] It must be stressed that statistics and predictions of survival and morbidity rates in newborns should be viewed with caution. For example, the definition of "morbidity" or "disability" may differ from a study to another. Studies assess such a concept by using different definitions of what may constitute major impairments and they may cover different periods of time. The role and the limits of statistics are a major concern in this field. See *infra* Part III, section C, 2.2 and note 164.

[9] K.C. Glass, "Ethical Issues in Neonatal Intensive Care: Perspectives for the Neurologist" (2002) 9(1) Seminars in Pediatric Neurology 35 at 35; K.J. Barrington, "Hazards of systemic steroids for ventilator-dependent preterm infants: What would a parent want?" (2001) 165(1) CMAJ 33.

today in situations where, twenty years ago, they would certainly have perished within hours or at best months.

This has raised strong ethical and legal controversies about neonatal intensive care, particularly in relation to severely defective newborns, that is, infants who are not likely to survive without surgical or medical intervention.[10] Are we improving survival rates of severely defective infants at the cost of contributing more disabled individuals to society?[11] What constitutes over-treatment and when should decisions to withdraw or withhold treatments be made? What is the right choice for a particular infant? What constitutes "a life worth living"? Who is the appropriate decision-maker?

The complexity of these issues cannot be denied. In practical terms, decisions have to be made in neonatal intensive care units (and in delivery rooms), while there is no medical and social consensus on ethical standards for treatment of defective

[10] For this discussion, "severely defective newborns" include very premature, ELBW, VLBW and severely handicapped infants.

[11] Bregman notes that "a more optimistic view is that we are creating a greater number of intact survivors": J. Bregman, "Developmental Outcome In Very Low Birthweight Infants, Current Status and Future Trends" (1998) 45(3) Pediatric Clinics of North America 673 at 676. However, he does not define an "intact survivor". Does such a category include premature and VLBW infants who are not suffering from so-called severe handicaps but remain "prone" to rehospitalisation early in life, slow growth, feeding problems, visual difficulties and potential learning-related and behavioural problems at school age? Such potential outcomes have been described in many studies: see for example: C. Gaugler *et al.*, "Rétinopathie du prématuré: étude rétrospective sur une période de dix ans au CHU de Strasbourg"; R.S. Sauve *et al.*, "Before Viability: A Geographical Based Outcome Study of Infants Weighing 500 Grams or Less at Birth" (1998) 101(3) Pediatrics 438; S. Saigal *et al.*, "Psychopathology and social competencies of adolescents who were extremely low birth weight" (2003) 111 (5 Pt 1) 969. Moreover, Bregman's optimism is questionable when one considers the survival of infants who are not only premature or tiny but also congenitally defective. By definition, these infants cannot be "intact survivors".

newborns.[12] Moreover, uncertainty regarding medical prognosis for imperiled neonates dramatically increases the controversies.[13]

Furthermore, in the decision-making process, the neonate does not exist "in isolation."[14] The newborn exists in a familial, social, cultural, and medical setting where its rights compete with those of others. In this context, physicians may be put in a difficult position. They must balance concomitant and perhaps competing duties such as a duty to provide medical care, a duty to respect the standards of care, a duty to respect the infant's rights and best interests, and a duty to respect parental authority. These duties may obviously become the source of tremendous conflicts where practices may oppose law, law may conflict with ethics, and ethics may disagree with practices.[15]

This thesis will discuss the notion of "person" and address the scope and consequences of the recognition of the moral and legal personhood of very defective neonates, particularly in the context of the requirement to provide medical care to these infants. It is my contention that the existence and particularly the scope of a duty to treat the most defective neonates cannot be assessed without considering the concept and significance of "person" and the different perceptions attached to this notion.

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[12] K.C. Glass, *supra* note 9 at 35.

[13] One of the most striking issues in NICUs is precisely the question of prognosis: which infant would die and which one would likely survive but with potentially severe disabilities?

[14] E.H.W. Kluge, "Deliberate Death In The Neonatal Setting: An Ethical Analysis" (1999) 23(5 & 6) Legal Medical Quarterly 1 [hereinafter: E.H.W. Kluge, "Deliberate Death"] at 12.

[15] E.H.W. Kluge, "Giving The Hemlock: A Policy Proposal" (1999) 23(5 & 6) Legal Medical Quarterly 35 [hereinafter: E.H.W. Kluge, "Giving The Hemlock"] at 35.

Do we consider very defective neonates as "full" persons, namely as actual patients who have a right to be treated in the same way as other persons? Certainly, one of the most radical ways of denying the existence of such a right or to limit seriously its scope could be to negate the personhood of newborns, particularly of those whose condition does not seem compatible with life.[16] If such newborns are not full persons, the rights and concomitant obligations owed to them may be challenged.

Such a proposal may seem deeply disturbing. However the moral status of very defective neonates remains a contentious issue. In particular, moral personhood and its implications are still debated and debatable concepts. In this respect, Part II of this thesis proceeds by presenting an overview of the various ethical theories which have been proposed in relation to moral personhood. I will outline this debate and contend that moral personhood is on no account a useless and impractical concept which has lost all relevance in reality. However, I will assert that moral personhood cannot constitute a *sufficient* ground to assess the existence and the scope of a moral duty to treat severely defective infants.

In the face of ethics, religion, philosophy and cultural traditions, legal doctrine has been struggling to define the starting point of legal personhood and its implications. In this respect, the legal status of the neonate sits against a varied and evolving background that cannot be ignored. It will be shown that against this background the "law of persons" has become fragmented and confusing.

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[16] For instance, should an attempt be made to resuscitate an infant born at 22 or 23 weeks of gestation, an infant weighting less than 500g or an anencephalic child?

As a matter of fact, the definition of the beginnings of legal personhood has been challenged by recent debates pertaining to foetal rights and abortion. By assessing the rights of the unborn child, especially its right to life, courts have come to consider the beginning of legal personhood on the ground of the so-called "born alive and viable" rule. I contend in Part III that in Canada and the United States, political and social pressures have led the courts and legislatures to manipulate and interpret this rule to such an extent that it has become an ambiguous legal tool. In this respect, it is striking to note that the potential impact of this situation on the legal status of very defective neonates themselves has rarely been assessed. In any case, the passage from the status of foetus, namely a non-person, to that of neonate who should be treated as a legal person occurs today in muddy legal waters.

There is very little disagreement over the legal personhood that neonates enjoy under North-American law. It will be demonstrated in Part III, through a review of selected cases in Canada and the United States,[17] that in contrast with foetuses, despite a few exceptions, courts have rarely openly challenged the legal personhood of defective neonates but have focused instead on the analysis of their "best interests".

However, the scope of the recognition of the legal personhood of very defective neonates and the consequences that recognition has on the demands and limitations of a duty to treat are less clear. Part III concludes by stressing that in the context of the cessation or non-initiation of medical care provided to very defective neonates, it

[17] A few examples or comments related to status of neonates in other developed countries will however be provided when relevant.

remains difficult to determine how and to what extent treatment should be given to such neonates in order for them to be treated as full *moral* persons, even though they are regarded as full *legal* persons.

Thus, it is my contention in Part IV that the claim that very defective neonates are full legal persons does not preclude ambiguity on the demands and limitations of a duty to treat severely defective newborns. It is well-known that physicians have a duty to treat their patients. However, this does not imply that a doctor has a duty to provide whatever treatment the patient or his/her surrogate decision-makers may request.[18] Both families and physicians must act in the patient's "best interests". However, what constitutes the best interests of severely defective neonates is controversial. I submit in this part that a "best interests" analysis often involves considerations and criteria that are closely related to the various social and ethical perceptions of the concept of "person". Courts have refused to consider these criteria to delineate the beginnings of legal personhood; however, these considerations and criteria have a significant impact in practice. The conclusion of Part IV is that it is important to be aware that, practically, an analysis of the best interests of a very defective neonate may be influenced by judgements based upon comparative social worth, or religious, political, cultural, and personal considerations which may endanger a full recognition of the personhood of neonates.

[18] E.I. Picard and G.B. Robertson, *Legal Liability of Doctors and Hospitals in Canada* (Toronto: Carswell Thomson Professional Publishing, 1996) at 265.

The fundamental conclusion of this thesis is that to a certain extent, courts have unsuccessfully attempted to maintain a clear divide between the legal definition of the "person" and the moral and social perceptions of that term. In the case of very defective neonates, the definition and the scope of legal personhood may be fraught with ambiguity and inconsistencies.

II. THE ETHICAL STATUS OF THE SEVERELY DEFECTIVE NEONATE

A. The implications of "moral personhood"

The existence and particularly the scope of a duty to treat the severely defective newborn cannot be assessed without firstly considering the concept and significance of "person". This is because the status of being a "person" carries with it significant legal protection and a strong moral recognition. Qualifying as a person has immediate implications for the individual neonate and broader consequences for associated bioethical issues.[19] Thus, it is undeniably true, as argued by Keyserlingk, that "to talk about what patients as persons may do, how they should be treated and what they are entitled to, logically calls for some prior thinking about what counts as a person".[20]

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[19] As stated by S. Aksoy: "The consequences of this discussion are vitally important, as they may help to articulate more adequate arguments on some bioethical issues, like the definition of the moral status of the embryo, abortion, IVF (test tube babies), embryo research, organ transplantation and terminating the life of patients in PVS": S. Aksoy, "Personhood: A Matter of Moral Decisions" (1997) 7(1) Eubios Journal of Asian and International Bioethics 3: http://www.biol.tsukuba.ac.jp/~macer/EJ71/EJ71B.html (accessed August 2003) at 3.

[20] E.W. Keyserlingk, for the Law Reform Commission of Canada, *Sanctity of Life or Quality of Life in the Context of Ethics, Medicine and Law* (Quebec: Supply and Services Canada, 1979) [hereinafter: E.W. Keyserlingk, *Sanctity of Life or Quality of Life*] at 76. See also J. Harris, *The Value of Life* (London: Routledge & Kogan Paul, 1985) at 7.

The definition of personhood is one of the most controversial notions in bioethics.[21] Further, controversy arises as to how personhood influences the ascription of legal and moral rights, and to what extent. Some commentators have argued that those who do not qualify as persons do not count morally and thereby do not possess any rights.[22] Conversely, others have claimed that, in any case, even "non-persons" may deserve some protection and thus possess such rights.[23]

These issues have been the crux of the debate pertaining to the questions of the moral and legal status of the embryo and the foetus, in which field controversy is still raging and is beyond the scope of this paper. However, I submit that considerations and arguments put forth in the frame of the debate regarding abortion and foetal rights are of undeniable relevance when it comes to assessing the status of very defective neonates themselves.

Moreover, the concept of personhood has been challenged by technological and medical progress. As discussed below, there is no doubt that the legal notions of "live birth" and especially of "viability", which have been used to demarcate the beginnings of personhood, have become more and more difficult to handle. This may lead to a

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[21] It raises contentious questions such as: when (and where) does human life begin and from when does society wish to protect this life? Are all human beings persons? If not, when does a human become a person? See *infra*, section B.

[22] Consequently, as stated by Baroff, some authors have come to the conclusion that the right to kill very defective infants could be justified on the grounds that a newborn has not yet achieved the status of "person": G.S. Baroff, "Eugenics, 'Baby Doe', and Peter Singer: toward a more 'perfect' society" (2000) 38(1) Mental Retardation 73 at 73.

[23] See M.A. Warren, "The Moral Significance of Birth" in E. Boetzkes and W.J. Waluchow, eds., *Readings in Health Care Ethics* (Ontario: Broadview Press Ltd, 2000) at 270.

considerable amount of useless confusion in a field where broader key values such as respect for human life and human dignity have emerged.

My intent is not to present an exhaustive review of the arguments linked to the beginnings of personhood, but to show that, ethically and legally, personhood and its implications are still debated, which has important ramifications for very defective neonates. Although there seems to be very little disagreement over the moral and legal personhood a newborn enjoys,[24] I contend that the moral status of very defective neonates remains ambiguous. In any case, one must recognise the importance of such a concept and remain vigilant for it could be used to justify denying very defective infants the protection of the law and their right to be treated as any other patient. Thus, one has to keep an eye on ethical theories and legal mechanisms that, in a world where disability is still believed to diminish personhood,[25] may threaten the moral and legal status of defective infants.

B. Moral personhood and the neonate

1. Overview of extreme positions

It has been argued that all newborn infants, even those who are born very immature or severely handicapped, are regarded as persons in common moral conviction.[26]

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[24] M.L. Gross, "Abortion and Neonaticide: Ethics, Practice and Policy in Four Nations" (2002) 16(3) Bioethics 202 at 216 [hereinafter: M.L. Gross, "Abortion and Neonaticide"].
[25] G. Landsman, "Emplotting children's lives: developmental delay vs. disability" (2003) 56 Social Science & Medicine 1947 at 1947-8.
[26] M.A. Warren, *supra* note 23 at 274; M. L. Gross, "Abortion and Neonaticide", *supra* note 24 at 216.

However, as discussed below, a significant number of philosophers, scientists and ethicists arguing about the definition of personhood and the beginning point of a human individual's life have concluded that defective neonates do not meet the criteria for human personhood. Thus, it has been suggested that significant moral value or basic human rights, such as the right to life, are not intrinsic but are conferred and earned once certain pre-conditions have been met.

Fletcher, in the seventies, initially presented not less than 15 points that make a human being a "person", including minimum intelligence, self-control, sense of time, sense of futurity and of the past, the capacity to relate to others, and even curiosity.[27] Using such criteria, it is difficult to argue that any neonate is a person.[28] Other authors have used the criterion of "self-awareness". According to Feinberg and Baum Levenbook, for example, persons are those who are conscious, have a concept and awareness of themselves, are capable of experiencing emotions, can reason and acquire understanding, can plan ahead, can act on their plans, and can feel pleasure and pain.[29]

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[27] J. Fletcher, *Humanhood: Essays in Biomedical Ethics* (Buffalo, New York: Prometheus Books, 1979) at 12-16.

[28] As might be imagined, these criteria motivated great opposition. See for example E.W. Keyserlingk, *Sanctity of Life or Quality of Life, supra* note 20 at 96-99. Keyserlingk underlines, notably, that it would be impossible to use most of those criteria as 'operational criteria'. He wonders, for instance: "What sort of empirical data or tests would one use to establish with any exactitude that someone has for instance 'a sense of futurity' or 'curiosity', or 'self control'?": *ibid.* at 98. It is worth stressing here that Fletcher himself attempted to tone down the implication of his theory by stating ambiguously that: "[c]areful and candid analysis will show that deciding whether and when an infant is a person is not the determinative question. The right one is, 'Can a person's life ever be ended ethically?' It all turns on the issue of whether the value of a human life is absolute or relative": J. Fletcher, *supra* note 27 at 146.

[29] J. Feinberg and B. Baum Levenbook, "Abortion" in T. Regan, ed., *Matters of Life and Death, New Introductory Essays in Moral Philosophy* (New York: McGraw-Hill, Inc., 1993) at 197-213.

Similarly, Engelhardt argues that:

> Not all humans are self conscious, rational and able to conceive the possibility of blaming and praising. Foetuses, infants, the profoundly mentally retarded and the hopelessly comatose provide examples of nonpersons. They are members of the human species but do not in and of themselves have standing in the moral community. ... For this reason it is nonsensical in general secular terms to speak of respecting the autonomy of fetuses, infants, or profoundly retarded adults. ... Treating such entities without regard for that which they do not possess, and never have possessed, despoils them of nothing that can have general secular standing. They fall outside the inner sanctum of secular morality.[30]

Buchanan and Brock partially share such a viewpoint. According to them, "personhood and the basic rights we ascribe to persons require certain minimal *cognitive capacities* which even normal infants lack".[31]

Self-awareness is also a concept used by Harris, who asserts that a person is any being capable of valuing its own existence.[32] In order to value its own life a being would have to be aware that it has a life to value.[33] Harris concludes that "creatures" that cannot value their own existence cannot be wronged by being killed "for their death deprives them of nothing that they can value".[34]

There is no doubt that major concerns arise from such theories: where is the exact point at which an infant acquires its personhood (or self-awareness), and thereby its right to life? Tooley has gone so far as to argue that there is no moral offence in ending a human life up to about a few months after birth because earlier than that the

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[30] H.T. Engelhardt, *The Foundations of Bioethics* (New York: Oxford University Press, 1996) at 139, 239.
[31] A.E. Buchanan & D.W. Brock, *Deciding for Others: The Ethics of Surrogate Decision Making* (Cambridge, New York, Victoria (AU): Cambridge University Press, 1990) at 260. However, the authors emphasize that "lack of personhood does not imply lack of moral status altogether": *ibid.* at 160.
[32] J. Harris, *supra* note 20 at 18-19.
[33] *Ibid.* at 18.
[34] *Ibid.* at 19.

newborn has not yet become a person.[35] He argues that the question where to draw the line of the beginnings of self-awareness is not troubling for "in the vast majority of cases in which infanticide is desirable, its desirability will be apparent within a short time after birth".[36] Thus, Tooley maintains that infants "do not have a right to life" and that infanticide is therefore a morally acceptable practice.[37] In the same vein, Singer suggests that the newborn is only a potential person, but not yet an actual one. As such, killing a newborn does not carry the same moral weight as killing an adult. It is worth noting that Singer's henceforth famous pronouncement that "[t]he life of a newborn baby is of less value to it than the life of a pig, a dog or a chimpanzee" has provoked vitriolic reactions.[38] Similarly, Weir supports the idea that the neonate is a

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[35] M. Tooley, "Abortion and Infanticide" in P. Singer, ed., *Applied Ethics* (Oxford: Oxford University Press, 1985) at 84 and E.W. Keyserlingk, *Sanctity of Life or Quality of Life, supra* note 20 at 98. See also James Park and his revealing so called "Wink Test for Infant Self-Consciousness". Park wonders when does self-consciousness emerge in babies and states: "When you have a baby's attention, wink at it. If the baby attempts to wink back, it must be aware that it exists and that it is another person like the one winking at it": J. Park, "When is a Person? Pre-Persons and Former Persons" (undated) in Part II, lit. A. "The Wink Test for Infant Self-Consciousness": http://www.tc.umn.edu/~parkx032/PERSON.html (accessed February 2003). We may doubt that a "no wink, no personhood" rule is a credible suggestion!

[36] M. Tooley, *supra* note 35 at 84.

[37] Tooley also asserts that: "... having a right to life presupposes that one is capable of desiring to continue existing as a subject of experiences and other mental states. ... So an entity that lacks such a consciousness of itself as a continuing subject of mental states does not have a right to life": *ibid.* at 69. See also M. Tooley, "A defence of abortion and infanticide" in J. Feinberg, ed., *The Problem of Abortion* (California: Wadsworth Publication Company, 1973) at 51.

[38] See, for example, M. Oppenheimer, "Who lives? Who dies? (The utility of Peter Singer)" (2002) Christian Century: www.findarticles.com (accessed January 2003) and G. Baroff, *supra* note 22 at 73-74. Any research on the web about Peter Singer will lead the reader to articles describing the vociferous outcry of protest that followed Singer's arrival at Princeton University in September 1999 as a professor of bioethics. Singer's disturbing and provocative pronouncement, taken out of context, may be misleading and may not faithfully reflect Singer's viewpoint. In full, Singer states: "If the fetus does not have the same claim to life as a person, it appears that the newborn baby does not either, and the life of a newborn baby is of less value to it than the life of a pig, a dog or a chimpanzee is to the nonhuman animal. If we can put aside these emotionally moving but strictly irrelevant aspects of the killing of a baby we can see that the grounds for not killing persons do not apply to newborn infants.": P. Singer, *Practical Ethics*, (Cambridge: Cambridge University Press, 1993) at 87. It has to be stressed that Singer has always been a fervent supporter of the animal-rights movement. Singer maintains that all sentient beings, human or not, are entitled to equal consideration for their comparably important interests (see A.M. Warren, *supra* note 23 at 273). In any case, Singer does not mean that the newborn baby is not worthy of protection, but he believes that in cases of severe abnormality, parents, in

potential person only and therefore does not have the same moral status that actual persons do. Nevertheless, Weir stresses that, as potential persons, neonates have *prima facie* claims to life and the medical treatment necessary to prolong life.[39]

According to Kluge's view, the moment of personhood occurs when there is a sufficiently developed nervous system to constitute potential for self-awareness. He suggests that the material basis of self-awareness resides in the nervous system and specifically the brain. Thereby, "a neonate can count as a person if and only if his brain development has progressed to the extent that the cerebral centers medically identifiable as the basis of self-awareness in normal individuals are present."[40] This leads Kluge to claim that the recognition of such a definition would avoid the creation of any ethical problem regarding anencephalic infants and neonates who are severely brain-damaged.[41]

Nevertheless, and perhaps paradoxically, Kluge stresses that "the radically defective neonate is nothing more nor less than an incompetent person"[42] and that "[t]he neonate is no exception. He has the full complement of rights that belong to other persons".[43]

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consultation with physicians, should be permitted to terminate a newborn's life. As we will see below, without sharing Singer's opinion about the definition of personhood and its consequences, other authors have reached comparable conclusions.

[39] R.F. Weir, *Selective Nontreatment of Handicapped Newborns: Moral Dilemmas in Neonatal Medicine* (New York, Oxford: Oxford University Press, 1984) at 194. Weir adds that when decisions are made to terminate a birth-defective infant's life, "such decisions should be made with sadness, reluctance and regret": *ibid.* at 194.

[40] E.H.W. Kluge, "Deliberate Death", *supra* note 14 at 15.

[41] *Ibid.* at 15. See also *infra*, Part III, section D, 2.1.

[42] J.E. Magnet and E.H.W. Kluge, *Withholding Treatment from Defective Newborn Children* (Cowansville, Quebec: Brown Legal Publications inc., 1985) at 189.

[43] E.H.W. Kluge, "Deliberate Death", *supra* note 14 at 4.

The debates pertaining to the beginnings of moral personhood have not only focused on the moral status of neonates. Considerations and arguments regarding abortion, foetal rights, and the moral status of foetuses are also relevant when it comes to assessing the status of very defective neonates themselves. Obviously, the commentators who support the ascription of a full measure of personhood to foetuses are not prone to challenge the personhood of neonates. In this respect, other proposed litmus tests of "personhood" such as the "attainment of sentience" and "stage of viability" theories have been proposed. Supporters of these theories suggest that a foetus becomes "fully human"[44] sometime after brain development has begun, but they insist on the moment when it becomes capable of experiencing sensations as pain[45] or at the point at which the foetus becomes viable. According to these theories, the sentience[46] or viability[47] of infants make a difference to how they should be treated, by contrast with a fertilized ova or a first trimester foetus. It has to be noted that, to those who accept such theories, "birth can make little difference to the moral standing of the fœtus/infant", for "[n]ewborn infants have very nearly the same intrinsic properties as do foetuses shortly before birth".[48]

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[44] A "fully human" entity must be understood here as "a person". However, one has to keep in mind that, as stated (and criticized) by O'Rourke (ed.), attempts have been made to delineate a difference between the human person and the human being: see "Baby Theresa: 'The Good That Could Be Done'" in K. O'Rourke, ed., *A primer for Health Care Ethics, Essays for a pluralistic society* (Washington D.C.: Georgetown University Press, 2000) at 169. See also H.T. Engelhardt who states: "Not all humans are persons": H.T. Engelhardt, *supra* note 30 at 138.

[45] H.T. Engelhardt, *supra* note 30 at 144.

[46] It has been shown that preterm neonates seem even more sensitive to pain than do more mature infants (see for example: R. Grunau Eckstein *et al.*, "Demographic and Therapeutic Determinants of Pain Reactivity in Very Low Birth Weight Neonates at 32 Weeks' Postconceptional Age" (2001) 107(1) 105). However, in the late 80s, the infant's ability to experience pain was highly underestimated.

[47] The concept of "viability" will be developed later in this thesis. See *infra*, Part III, Section C, 2.2.

[48] M.A Warren, *supra* note 23 at 271.

The above theories have been fiercely opposed. Schwarz, for instance, argues that the theories advanced by writers such as Fletcher, Tooley and Singer support a "functioning" person theory implying that only human beings who have achieved a certain degree of development and met certain conditions such as consciousness, rationality, capacity to communicate or to experience pleasure or pain, count as real persons. By doing so, these writers divide humanity into two separate categories: "persons" and "mere human beings", who are moral non-persons. According to Schwarz this is a dangerous and discriminatory distinction.[49]

Basically, pro-life authors, on the ground of religious sanctity of life argumentation, stress that full humanness begins at conception and that human life is intrinsically sacred and may not be taken under any circumstance.[50]

The history of the belief that there is a spiritual side of a human individual goes far back with Plato and Aristotle.[51] Since then, some are still searching for the exact time of "ensoulment" (at conception, birth, or even later?), for "when the body meets with

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[49] S.D. Schwarz, *The Moral Question of Abortion* (Manchester: Sophia Institute Press, 1990): http://www.ohiolife.org/mqa/toc.asp (accessed April 2003) at Chapter 7.2 and 7.4. See also a critique of this "functionalist" theory by A.H. Konsen, "Note: Are We Killing The Weak to Heal The Sick? Federally Funded Embryonic Stem Cell Research" (2002) 12 Health Matrix 507 at 533 and K. O'Rourke, ed., *supra* note 44 at 169.

[50] For a presentation of Catholic vitalism, see D.C. Thomasma, "The Sanctity-of-Human-Life Doctrine", in E.D. Pellegrino & A.I. Faden, eds., *Jewish and Catholic Bioethics, An Ecumenical Dialogue* (Washington D.C.: Georgetown University Press, 1999) at 59-60. According to another theory, so called "Consistent Ethics of Life", each form of human life is considered to be "innocent" and worthy of respect until a wilful act causes the loss of innocence for example by becoming an unjust aggressor against others through murder. Then, the person loses the right to his or her life under certain strict conditions: *ibid.* at 60-62. This obviously could not be the case of newborns. See also C.E. Rice, who states that "we have a duty to save whatever lives we can" *in* "Abortion, Euthanasia, and the Need to Build a New 'Culture Of Life'" (1998) 12 ND J.L. Ethics & Pub Pol'y 497 at 520. For discussion of the sanctity of life theories, see also *infra* Part IV, Section A.

[51] S. Aksoy, *supra* note 19 at 4.

the soul it comes to be a human person, with all the attendant rights, especially his basic right to life."[52]

2. *Beyond strict personhood*

The various theories of personhood, despite their bewildering diversity of viewpoints, all cluster around a common center of essential attributes or intrinsic properties relating to the capacity for thought and self-awareness.[53] All the above arguments and theories have been developed and qualified. It might well be prudent to admit that an attempt to reach a full knowledge and understanding of the many opinions that have been expressed in that field and their implications can lead to a confused and misleading picture of the debate.

Practically, perceptions of personhood are not based on intrinsic or universal criteria, but are contingent upon *social recognition* which "speaks of social values".[54] Moreover, there can be gradations in personhood.[55] Societies may deny full

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[52] *Ibid.* at 4. See also F. J. Beckwith, "Answering The Arguments For Abortion Rights. Part 4: When Does a Human Become a Person?", (Summer 1991) Christian Research Journal 28: www.iclnet.org/pub/resources/text/cri/cri-jrnl/crj0141a.txt (accessed February 2003). It has to be stressed that adamant answers cannot be found on a religious or spiritual ground either. Firstly, different strains of faith lead to different theories. Moreover, people sharing the same faith may well hold different viewpoints about the very beginning of personhood and the moral status of neonates. To take one example, a strain of Jewish interpretation holds that the death of an infant during the first thirty days of life should be considered as miscarriage: H.T. Engelhardt, *supra* note 30 at 147.

[53] A.J. Friedman, "Taking the camel by the nose: the anencephalic as a source for organ transplants" (1990) 90 Colum. L. Rev. 917 at 956.

[54] G. Landsman, *supra*, note 25 at 1950.

[55] *Ibid.*

personhood, and even the right of life itself, to infants born with anomalies.[56] But they can also, as stated by Engelhardt, admit a "social perception of personhood" involving *respect* for those who, according to some of the theories outlined above, would not qualify as persons strictly.[57] In the same way, by discussing neonatal euthanasia, Sklansky asserts that "personhood in the strict sense denies to all newborn infants a right to life, whereas personhood in the social sense entitles all newborn infants to a right to life".[58] Personhood has also been described as a "matter of relationships" that does not depend on intrinsic attributes.[59] In this respect, a very defective neonate, though incapable of rationality, self-control or other attributes, would be a "person" when she or he would be unique and "irreplaceable" to others (e.g. parents).[60]

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[56] Ethnographic research suggests that the denial of full personhood, and even of life itself, to infants born with anomalies is not uncommon: *ibid.* at 1949-50. This is not only characteristic of traditional societies in which there is a high rate of infant mortality, but, as stated by some commentators, the denial of full personhood to individuals with disabilities is also well documented in the United States, Israël and other developed countries: *ibid.* at 1950. According to O.W. Jones, "[t]he local moral intuition that infanticide is cruel and inhuman is in fact a quite recent and minority view". This commentator argues that infanticide remains today more disturbingly common than is generally acknowledged: "In a modern-day South American country, for example, many poor Catholics reportedly view contraception as a bigger sin than infanticide, and not infrequently kill their seventh or eighth infant.": O.W. Jones, "Evolutionary Analysis in Law: An Introduction and Application to Child Abuse" (1997) 75 N.C.L. Rev. 1117 at 1199.

[57] "Unlike persons strictly, who are bearers of both rights and duties, persons in the social sense have rights but no duties. That is, they are not morally responsible agents, but are treated with respect (ie, rights are imputed to them) in order to establish a practice of considerable utility to moral agents: a society where kind treatment of the infirm and the weak is an established practice... The social sense of a person is a way of treating certain instances of human life in order to secure the life of persons strictly.": H.T Engelhardt, "Medicine and the concept of person", in T. Beauchamp and S. Perlin, eds., *Ethical Issues in Death and Dying* (New Jersey: Prentice-Hall, 1978) at 277-8. This excerpt is quoted in M. Sklanski, "Neonatal euthanasia: moral considerations and criminal liability" (2001) 27 Journal of Medical Ethics 5 at 7.

[58] M. Sklanski, *supra* note 57 at 7. We can also refer to Kluge who, according to Weir, recognizes that "babies are persons in our sense of the term", but also states that "a being that lacks 'the constitutional capabilities for rational, symbolic thought and self-awareness is not a person'": R.F. Weir, *supra* note 39 at 151.

[59] As noted by E.W. Keyserlingk, *Sanctity of Life or Quality of Life*, *supra* note 20 at 85-86.

[60] *Ibid.* at 86

In any case, a theoretical dichotomy between persons who have a full moral value and who have rights, and non-persons who have no moral value and no rights at all is too simplistic an approach. In this respect, the debate about the moral status of embryos and foetuses is quite revealing: one of the most striking features of this issue is that the questions of what can be done to the embryo and the foetus remain unanswered by assuming that they are persons or non-persons. Most supporters of embryo research, arguing that the embryo is not a person, ultimately claim that it must nevertheless be treated with "special respect because it is a genetically unique living human entity that might become a person."[61] Moreover, in the abortion debate, it has also been suggested that even if the foetus is a person, it would not mean that killing it would be morally wrong in all circumstances.[62] In other words:

> The moral claims of late foetuses and of babies are not exhausted by any rights depending on their qualifying as persons. Perhaps they are not persons, and have less of the required self-consciousness than some nonhuman animals. But we have reasons, to do with ourselves rather than them, for not treating them as merely disposable.[63]

It has to be noted that, in parallel, such notions as the respect for human life and human dignity can potentially relegate the notion of personhood to a secondary

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[61] See for instance: Ethics Committee of the American Society for Reproductive Medicine, "Ethical considerations of assisted reproductive technologies", (1994) 62(1Suppl) Fertility and Sterility 1S, in Chapter 10: *The Moral and Legal Status of The Preembryo* at 33S. According to the same committee, the moral (and even legal) status of the embryo should therefore be considered "on its own merits": *ibid.* at 32S. The notion of "special respect" is obviously a nebulous concept on which a lot could be (and has been) said. Regardless of how doubtful this concept may be, it shows in any case how, in the final analysis, the absence of personhood does not involve a complete absence of protection or moral recognition.

[62] L.M. Hinman, referring to J.J. Thomson and J. English in *Contemporary Moral Issues: Diversity and Consensus* (University of San Diego, 1999): http://ethics.sandiego.edu/lmh/cmi/cmi2.doc (accessed April 2003) at 54-55, 64. See also F.C. DeCoste, "Winnipeg Child and Family Services (Northwest Area) v. D.F.G.: The Impossibility of Fetal Rights and the Obligations of Judicial Governance" (1998) 36 Alberta L. Rev. 725 at 731.

[63] K. Walsh, "Note: The Science, Law, and Politics of Fetal Pain Legislation", (2002) 115 Harv. L. Rev. 2010 at 2030.

position. Indeed, the concept of respect for human dignity may be broad enough to protect those who would not qualify as "persons" but who remain nevertheless intrinsically human.[64]

Therefore, while one may agree or disagree as to the moral personhood of very defective infants, in any case, the practical issue still remains as to whether they must be treated and how. Consequently, in the context of a right to treatment, it has been suggested that the concept of "person" should be abandoned in relation to very defective neonates. Elizabeth Wolgast argues that it is more important to understand our responsibilities to protect and care for infants than to insist that they have exactly the same moral rights as older human beings.[65] In the same manner, Kuhse claims that what is important is not that a patient is human (and therefore should have her life sustained) but rather to ask questions about the quality and kind of the patient's life.[66] From a practical point of view, "the ethical principle of *respect for persons* is a more important concept than *what counts as a person*".[67]

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[64] However, it has to be noted that there are different perceptions of human dignity. The concept of human dignity may be attached to the dignity of "persons", namely to those individuals only who possess certain features or capacities. In this viewpoint, personal dignity or dignity of "the person" is very close to the concept of personhood itself. Another conception of human dignity guarantees the dignity of each human being irrespective of the presence or absence of contingent features. As stated by Pullman, "to equate human dignity with individually referenced capacities reduces dignity to a shorthand form for rational autonomy, self-determination, self-control, and the like.": D. Pullman, "Dying with Dignity and the Death of Dignity" (1996) 4 Health L.J. 197 at 204. Thus, this author supports the concept of "basic dignity", as the idea "... that all human beings are worthy of moral consideration, irrespective of physical characteristics, mental capacity, or any contingent feature or circumstance ...": *ibid.* at 207.

[65] Quoted by M.A. Warren, *supra* note 23 at 276.

[66] H. Kuhse, *Sanctity-of-Life Doctrine in Medicine, A Critique* (Oxford: Clarendon Press, 1987) at 213.

[67] E.W. Keyserlingk, *Sanctity of life or quality of life*, *supra* note 20 at 102-3 (emphasis in original text). See also J. Harris, *supra* note 20 at 22, quoting Mary Warnock: "we would do better to remove the concept 'person' altogether from the debate. It is both confusing and redundant. [...] The question 'is he a person' is only another way of asking 'may I do what I want with him?'".

3. The personhood of neonates in the light of professional ethical guidelines

Very few explicit references to the personhood or the moral value of very defective neonates are made in professional and ethical guidelines issued in developed nations around the world that address neonatal intensive care and end-of-life decision-making.

In Canada, the recommendations issued by the Canadian Paediatric Society (CPS) in 1986 and reaffirmed in 2000[68] state that all infants "have *intrinsic value* and deserve our respect and protection", with the consequence that infants have a "justified claim to life and therefore to such medical treatment as is necessary to either improve or prolong life".[69]

No mention of such "intrinsic value" is made in the CPS's Joint Statement with the Society of Obstetricians and Gynaecologists of Canada on the Management of the woman with threatened birth of an infant of extremely low gestational age.[70] The CPS focuses on the limits of viability and concludes that since infants with a gestational age of less than 22 weeks cannot be expected to survive, "they should be given only compassionate palliative care".[71] No formal attempt is made to define the moral status of such premature babies.

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[68] Bioethics Committee of the Canadian Paediatrics Society, "Treatment decisions for infants and children" (1986, reaffirmed February 2000, revision in progress March 2002), Reference N° B86-01: http://www.cps.ca/english/statements/B/b86-01.htm (accessed March 2003).
[69] *Ibid.* (emphasis added).
[70] Canadian Paediatrics Society, Joint Statement with the Society of Obstetricians and Gynaecologists of Canada, "Management of the woman with threatened birth of an infant of extremely low gestational age" (1994, revision in progress March 2002): http://www.cps.ca/english/statements/FN/fn94-01.htm (accessed March 2003).
[71] *Ibid.*. See also P.J. Van Reempts *et al.*, *supra* note 1 at 238-9.

The same statement can be made as to the guidelines issued by the American Academy of Pediatrics (AAP).[72] Similarly, the British Medical Association mainly states that the same moral duties are owed to babies as to adults.[73] Like all the above guidelines, the British Association of Perinatal Medicine (BAPM) focuses on the best interests of the infant.[74]

More puzzling is the perception of neonates' personhood and its implication in France. The CCNE[75] focuses primarily on the necessity to safeguard and respect human dignity, stressing that "a child is obviously to be considered in the same way as any other human being" and that "ethical principles applying to a person can and must apply to a child".[76] The most recent recommendations issued by the French Federation of Neonatologists, calling for a so-called "ethics of responsibility", stress that beyond possible philosophical representations of the newborn infant, the first "movement" in

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[72] This may sound consistent in a country where a foetus itself gains a measure of legal personhood and a strong moral recognition at the beginning of the third trimester: see *infra* Part III, Section B, 2. See also M.J. Gross, "Abortion and Neonaticide", *supra* note 24 at 208, 210. It is worth noting that in 1999, the AAP Committee on Bioethics stated that "[w]ith recent advances in perinatal medicine, the pregnant woman and her fetus are increasingly viewed as two treatable patients": AAP, "Fetal Therapy – Ethical considerations (RE9817)" (1999) 103(5) Pediatrics 1061: http://www.aap.org/policy/re9817.html (accessed April 2003). An ethical viewpoint that considers foetuses as patients should obviously consider neonates themselves as patients, namely as full persons. The situation in the United States will be developed later in this paper (see *infra* Part III). For the AAP's guidelines pertaining to neonates, see: AAP, "Perinatal Care at the Treshold of Viability" (2002) 110(5) Pediatrics 1024: http://www.aap.org/policy/010107.html (accessed April 2003); AAP, "The Initiation or Withdrawal of Treatment for High-Risk Newborns" (1995) 96(2) Pediatrics 362: http://www.aap.org/policy/00921.html (accessed April 2003); AAP, "Ethics and the Care of Critically Ill Infants and Children (RE9624)" (1996) 98(1) 149: http://www.aap.org/policy/ 01460.html (accessed April 2003).

[73] British Medical Association (BMA), *Withholding and Withdrawing Life Prolonging Medical Treatment: Guidance for decision making*, (London: BMJ Books, 2001): http://www.bmjpg.com/withwith/contents.htm (accessed March 2003) in Part 3B, Section 14.1.

[74] BAPM, "Foetuses and Newborn Infants at the Threshold of Viability: A Framework for Practice" (2000): http://www.bapm.org/documents/publications/threshold.pdf (accessed May 2003).

[75] Comité Consultatif National d'Ethique pour les sciences de la vie et de la santé.

[76] CCNE, "Ethical considerations regarding neonatal resuscitation" (2000), Opinion n°65: http://www.ccne-ethique.org/english/pdf/avis065.pdf (accessed March 2003).

perinatal medicine must be to acknowledge that newborns are *patients* and must be treated as such.

According to the Federation:

> Ce geste initiateur [ie to qualify neonates as patients], véritable prise de position sur l'homme, dit en soi plus que toutes les tentatives de formalisation autour de la notion de personne, sur lesquelles des désaccords peuvent demeurer. Ce principe fondateur d'une reconnaissance de l'être humain déjà présent dans son inaccomplissement impose que le fœtus et le nouveau-né ne puissent être traités comme objet de soin, mais toujours comme sujet à qui nous devons des soins adaptés et proportionnés.[77]

Surprisingly, according to Ropert, recognising that neonates, whatever their gestational age or weight, are full human beings is clearly a courageous and singular philosophical position.[78] Thus, in France, as a patient whose human dignity must be recognised, any neonate has a right to be treated and, therefore, should have an individual right to be resuscitated, whatever his or her condition.[79] This "*a priori* of life" leads to a so-called "réanimation d'attente" that can be followed by a decision to withdraw or withhold further treatment, but also by active euthanasia.[80]

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[77] M. Dehan *et al.* pour la Fédération nationale des pédiatres néonatologistes, "Dilemmes éthiques de la période périnatale: recommandations pour les décisions de fin de vie" (2001) 8 Arch Pediatr 407 at 411.

[78] J.C. Ropert, "Les décisions de fin de vie en période périnatale: un débat professionnel, une question de société" (2001) 8 Arch Pédiatr 349 [hereinafter: J.C. Ropert, "Les décisions de fin de vie"] at 350.

[79] J.C. Ropert, "Les dilemmes éthiques des décisions de fin de vie en période périnatale" (2002) 9(Suppl.1) Arch Pédiatr 43s [hereinafter: "Les dilemmes éthiques"] at 47s.

[80] Recent studies have shown that French physicians admit with a significant frequency decisions to administer drugs with the purpose of ending the life of neonates. See M. Cuttini *et al.* for the EURONIC Study Group, "End-of-life decisions in neonatal intensive care: physicians' self-reported practices in seven European countries" (2000) 355 Lancet 2112.

One might be puzzled here: the philosophical French position that ascribes full moral personhood to neonates is precisely the one ultimately used to justify active euthanasia:

> Cette position philosophique a permis l'ouverture vers le concept de transgression de la morale et du droit concernant l'arrêt de vie, sublimation ultime de la reconnaissance de l'humanité entière du fœtus et du nouveau-né.[81]

With regard to such outcomes, it has been asserted that the ethical status of the very defective newborn remains ambiguous.[82] However, despite such potential ambiguity, most western ethical guidelines related to the care of very defective neonates do not explicitly address the concept of moral personhood. Guidelines mainly emphasise the infant's best interests and focus on the chances of intact survival considering current medical knowledge and technology. In other words, the moral personhood of very defective newborns does not seem to be a central consideration in ethical guidelines.

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[81] J.C. Ropert, "Les décisions de fin de vie", *supra* note 78 at 350.

[82] M. Mokhtari, *La relation médecin-parents dans les décisions de réanimation en service réanimation néonatale,* DEA d'éthique médicale et biologique (1996), Université René Descartes Paris V: http://www.inserm.fr/ethique/Travaux.nsf/ (accessed March 2003).

4. The practical impact of considerations pertaining to moral personhood

Given that most ethical and professional guidelines do not refer to moral personhood, why is it worth prolonging the debate by exposing extreme viewpoints on personhood that, at first sight, do not seem to have any significant impact? Considering the aforementioned guidelines, it could be tempting to assume that the ethical controversies surrounding the matter of personhood are of no interest in practice when one must decide to treat a very defective neonate or not. However, I contend that this is not the case.

The proposals to use anencephalic infants as organ donors illustrate this point. Some supporters of such a practice have argued that anencephalic infants could be regarded as living "non-persons", namely as biologically human entities that lack the prerequisite of personal life and thus full moral status. In their opinion, anencephalic newborns suffer from such damages that they merely do not have the capacity to become a person.[83] Under such a definition, anencephalic children can be considered as dead, notwithstanding the fact they do not meet the traditional (and legal) criteria of death. In practice, it also means that aggressive medical measures such as resuscitation

[83] According to Friedman, it is "obvious" that anencephalic infants constitute a class of humans that are "non persons" because they lack the capacity for the most minimal level of cogitation and social interaction. Thus, they cannot have any interest: J.A. Friedman, *supra* note 53 at 952. For references and critiques on such a viewpoint, see D.A. Shewmon *et al.*, "The Use of Anencephalic Infants as Organ Sources: A Critique" in A.L. Caplan and D.H Coelho, eds., *The Ethics of Organ Transplants, the current debate* (New York: Prometheus Books, 1998) at 99-100 and 102-5; J.D. Arras and S. Shinnar, "Anencephalic Newborns as Organ Donors: A Critique" in E. Boetzkes and W.J. Waluchow, eds., *supra* note 23 at 528-9 and M.Z. Pelias, "Anencephalic as Organ Donors" (1994): http://www.thefetus.net/main.htm (accessed May 2003).

and ventilation could be initiated, not in the benefit of the infant, but solely to preserve the quality of their organs.

In 1987, a research protocol entailing resuscitation of anencephalic infants at birth and maintenance of intensive care to protect organ viability until total brain death occurs was developed in Toronto and subsequently adopted by Loma University Hospital in California.[84] In 1995, the American Medical Association (AMA) issued a statement allowing the retrieval of organs from anencephalic neonates who were still alive under the current definition of death, on the basis that anencephaly precluded any possibility of consciousness. This policy was suspended due to fierce opposition.[85]

In Canada, the Bioethics Committee of the CPS clearly asked the question: should infants with anencephaly be regarded as *people*? It concluded that "an infant with anencephaly is a human being, albeit severely malformed, and therefore must be treated in the same way as any other human being".[86]

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[84] C. Lantz, "The Anencephalic Infant as Organ Donor" (1996) 4 Health Law Journal 179 at 190. For the details pertaining to the American protocol, see A.J. Friedman, *supra* note 53 at 931-6.

[85] C. Lantz, *supra* note 84 at 195. The Code of Medical Ethics of the AMA still states today that physicians may provide anencephalic neonates with ventilator assistance and other medical therapies that are necessary to sustain organ perfusion and viability until such time as the determination of death can be made in accordance with accepted medical standards, relevant law and regional procurement organisation policy: AMA, "Code of Medical Ethics", in B.A. Brody *et al.*, eds., *Medical Ethics: Codes, Opinions, and Statements* (Washington D.C.: BNA Books, 2000) at 21. On its side, the AAP does not exclude the use of anencephalic infants as organ donors, but believes that extreme caution should be adopted before adopting a policy permitting organ retrieval from anencephalic infants who retain brain stem function: AAP, "Infants with Anencephaly as Organ Sources: Ethical Considerations" (1992) 89(6) Pediatrics 1116: http://www.aap.org/policy/04790.html (accessed April 2003).

[86] CPS, "Transplantation of organs from newborns with anencephaly" (1990) 142(7) CMAJ 715: http://www.cps.ca/english/statement/B/b90-01.htm (accessed April 2003).

In its final recommendations, however, the Committee contented itself to "discourage" the provision of aggressive life support in the anticipation of brain death and to limit to a finite period the provision of medical treatments aiming to prolong organ viability.[87] This position statement is currently under revision and one may wonder what amendments will be proposed by the CPS Bioethics Committee. In any case, one must admit here that the full moral personhood of anencephalic infants is at stake.

Above all, the example of anencephalic infants demonstrates perfectly the practical impact of considerations related to moral personhood when it comes to assessing a defective newborn's best interests and his/her right to be treated. According to Buchanan and Brock, those "beings" who permanently lack the capacity for consciousness and whose good can never matter to them have no interests.[88] Consequently, the "best interests principle" does not apply to them.[89] Similarly, Munson's "non-interest" theory is also revealing: this author argues, avoiding the touchy concept of personhood, that anencephalic infants, because of their total lack of consciousness, have no "best interests" that should or even could be protected.[90] This obviously shows that criteria used by commentators such as Singer, Tooley or Fletcher

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[87] *Ibid.*

[88] A.E. Buchanan & D.W. Brock, *supra* note 31 at 129.

[89] *Ibid.* at 128. According to the authors, anencephalic infants and permanently unconscious patients are not "persons". In such cases, even prevention or palliation of discomfort is irrelevant, because such "beings" are permanently "bereft of all sentience and awareness": *ibid.* at 130. Similarly, the severely and permanently demented, who lack one or more of those cognitive capacities "that are widely thought to be the necessary conditions for personhood" are not "persons" either. However, they have a current interest "while alive in palliative care to relieve pain or suffering and to produce pleasure": *ibid.* at 197.

[90] Therefore, they can be considered as being dead, however they maintain life functions that are not compatible with the traditional brain death definition: R. Munson, *Raising the Dead, Organs Transplants, Ethics, and Society* (New York:Oxford University Press, 2002) at 92-3. See also: J.D. Arras and S. Shinnar, *supra* note 83 at 528-9.

to define moral "personhood" may actually be closely linked to the analysis of an infant's best interests itself.

In other words, even while one may agree on the moral personhood of anencephalic children or other very defective or premature infants, considerations such as consciousness, viability and the ability to communicate, to enjoy life, to feel pain are also used to assess their best interests, especially when it comes to evaluating their actual and potential quality of life and the scope of a duty to treat them. Moreover, viability itself is also a criterion that is integrated in an analysis of the standards of care owed to very defective neonates. Thus, a shift of focus has occurred: we do not talk directly about neonates as "persons" or about their "moral personhood", but about standards of care, quality of life, and ability to survive without tremendous damages. Does this threaten their moral status? One may hesitate when reading some clinical professors of pediatrics themselves evaluating neonates' interests as follows:

> An infant as a human being has an interest in not being wronged by being used as a means by which to satisfy someone else's ends. The infant has an interest *as all other young animals* do to being fed, caressed, and protected from the elements.[91]

The close relationship between a best interests analysis and some criteria used to define moral personhood will be developed in Part IV. However, one has to admit, at this stage of the discussion, that considerations about the moral personhood of very defective neonates have not lost their significance. Considering that there is no ethical and social consensus on the concept of personhood and its implications, one must

[91] D.K. Stevenson and A. Goldworth, "Ethical considerations in neuroimaging and its impact on decision-making for neonates" (2002) 50 Brain and Cognition 449 at 452 (emphasis added).

admit that there is no such thing as a correct or universal definition of a moral person. Moreover, the commonplace understanding of what it means to be a person is an evolving and versatile phenomenon in the face of religion, philosophy and cultural traditions. As developed below, it is against this background that legal doctrine and the law have struggled to define individuality and humanity.

I will first submit that in this struggle, legislators and courts have created a concept of legal personhood that is today challenged by the developments of medical science. Moreover, I contend that, most often, courts have carefully attempted to avoid any direct considerations related to moral personhood and have tried to create a clear divide between the legal definition of "person" and the social, philosophical and moral understanding of this concept. However, as developed below, such a dichotomy is misleading: in the context of a duty to treat very defective neonates, especially when it comes to ascertaining their best interests, the theories about moral personhood and the social perceptions of this concept may have significant implications that cannot be ignored in the legal framework.

III. LEGAL PERSONHOOD

A. Legal personhood: an evolving concept with evolving implications

Legal personhood has always been a basic building block and reference point in both the common law and civilist traditions.[92] The concept of legal person defines who or what the law will recognise as a being capable of having rights and duties. Thus, if one is not a legal person, one is "literally, outside of the law either as having no status (a non-entity) or as being an object (of property)".[93] As stated by Brettel Dawson: "[L]aw has not merely defined social relations, but *defined* the nature of the beings involved in them".[94] The definition of a "legal person" has evolved throughout history, whereby individuals have been classified and distinguished for special regulatory purposes in different contexts, cultures and traditions. Slaves[95], prisoners, disabled people[96], and women[97] were once treated as partially or wholly "non-persons". In times past, the killing of infants was often condoned by prevailing legal standards and sometimes

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[92] T. Brettel Dawson, "Law and the Legal Person", in T. Brettel Dawson, ed., *Women, Law and Social Change* (Carlton University, 4th Ed., 2002) http://www.lawsite.ca/ WLSC/ LegalPerson_w. htm (accessed February 2003) in Chapter 4, lit. B.

[93] *Ibid.*

[94] *Ibid.* (emphasis in original text).

[95] For an interesting analysis of the legal status of slaves and the evolving (and often incoherent) perception of this status, see "Note: What We Talk About When We Talk About Persons: The Language of a Legal Fiction" (2001) 114 Harv. L. Rev. 1745 [hereinafter: "What We Talk About When We Talk About Persons"] at 1747-50. (The author of this article is unknown.)

[96] See J.E. Magnet and E.H.W. Kluge, *supra* note 42 at 100-1. These authors state that it has been maintained that English law did once classify severely deformed infants as "monsters" and that it did not account such infants as "legal person". This position is supported by Friedman who states that the common law recognized a class of nonhuman beings, "monsters" who were the products of human conception but were not considered human beings: A.J. Friedman, *supra* note 53 at 949, 968. However, Magnet and Kluge oppose this viewpoint: in their opinion, upon the law, "monsters" could not inherit, but killing a monster would have been punishable as murder. Therefore, such disabled people and newborns were not lacking legal personality.

[97] In Canada, see *Winnipeg Child and Family Services (Northwest Area) v. G. (D.F.)*, [1997] 3 S.C.R. 925 [hereinafter: *Winnipeg v. D.F.G.*] at par. [118].

justified by the very idea that physically deformed infants were not real children or human persons.[98]

The legal status of the neonate lies within the framework of this evolving legal and cultural background. Moreover, nowadays, the definition of the beginning of legal personhood has been challenged by the debates pertaining to foetal rights and abortion. By assessing the rights of the unborn child, the courts have come to consider the starting point of legal personhood on the ground of the so-called "born alive and viable rule". However, "live birth" and "viability" are nebulous and controversial concepts that have been used and defined differently in many jurisdictions. In this respect, one has to admit that there is no coherent body of legal doctrine or jurisprudential theory regarding the legal concept of "person".[99]

I will demonstrate below that the judicial manipulations and disparate interpretations of the "born alive and viable" rule have occurred to the detriment of legal consistency. The result is that the traditional legal justifications that could once legitimate a distinction between the legal status of a late-term foetus and a very defective neonate are no longer compelling. The following concise review of cases pertaining to the

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[98] R.F. Weir, *supra* note 39 at 3-28, in particular 6, 7 and 19. See also A.J. Friedman, *supra* note 53 at 948. See also Amundsen, who stresses that it can be asserted categorically that there were no laws in classical antiquity, Greek or Roman, that prohibited the killing of the defective newborn. D.W. Amundsen adds: "Further, it is unlikely that there actually were any laws that classified exposure (as distinct from other forms of killing) of the healthy newborn as parricide or homicide, or prohibited the practice on other grounds, except, perhaps, in some limited regions or under unusual circumstances before the Christianization of the Roman Empire. If any such law or laws existed, there appears to have been little or no effort to enforce them": D.W. Amundsen, "Approaches of the Ancient World" in R.C. McMillan *et al.*, eds., *Euthanasia and The Newborn: Conflicts Regarding Saving Lives* (Dordrecht: D. Reidel Publishing Company, 1987) at 8.

[99] "What We Talk About When We Talk About Persons", *supra* note 95 at 1746.

legal status of the foetus in North-America[100] as contrasted against cases involving very defective neonates or older and severely sick children will show the difficulty of the law to keep a consistent approach toward legal personhood.

B. The legal status of the foetus

1. Canada

The jurisprudence pertaining to the rights of the embryo and the foetus in Canada outlines the legal beginnings of personhood in tort law and in civil law. As summarised by the Supreme Court of Canada in *Winnipeg Child and Family Services (Northwest Area) v. G. (D.F.)*:

> Once the child is born, alive and viable, the law may recognize that its existence began before birth for certain limited purposes. But the only right recognized is that of the born person. ... The position is clear. Neither the common law nor the civil law of Quebec recognizes the unborn child as a legal person possessing rights. This principle applies generally, whether the case falls under the rubric of family law, succession law or tort. Any right or interest the foetus may have remains inchoate and incomplete until the birth of the child.[101]

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[100] The legal status of the foetus is also debated in international law and other countries. Various international treaties and declarations related to human rights (some to which Canada is a party) contain provisions pertaining to the right to life and refer to "persons", "human being" or "everyone". The question whether such appellations include the foetus is controversial. However, a discussion of international law is beyond the scope of this thesis. One may simply state, as the Supreme Court of British Columbia did in 1999, that there is no consensus in the international community relating to the rights of the foetus and that "it is fallacious to suggest that there is any notion of customary international law recognizing that the right to life applies to the foetus": *R. v. Demers*, (1999-08-03) BCSC CC980044 at par. [71]: http://www.canlii.org/bc/cas/bcsc/1999/1999bcsc11241.html (accessed August 2003).

[101] *Winnipeg v. D.F.G.*, *supra* note 97 at par. [11, 15]. In this case, the Supreme Court of Canada, relying notably on the "live birth" rule which negates the personhood of unborn foetuses, refused to uphold the order issued by a superior court in Manitoba to detain and treat a pregnant woman – addicted to glue sniffing – for the purpose of protecting her foetus. The Court concluded that an order to detain a pregnant woman for the sake of her unborn foetus would require changes to the law which cannot properly be made by the courts and should be left to the legislature because "the legislature is in a much better position to weigh the competing interests and arrive at a solution that is principled and minimally intrusive to pregnant women": *ibid.* at par. [4, 56].

As early as 1933, the Supreme Court recognized in *Montreal Tramway Co. v. Léveillé* that while the injury to a foetus due to the negligence of a third party is actionable, any right of civil action, however, is contingent upon the child being born alive and viable.[102] Similarly, estate and property cannot pass to a newborn or its heirs before it has been born alive and viable.[103] In Canadian family law, a foetus appears to receive some protection, but the rights take effect and are perfected by "successful birth", namely once the child has been born alive and viable.[104] The "born alive and viable" rule is also currently used in car accident insurance and social insurance schemes. No life compensation may be granted for a deceased foetus which is not born alive and viable after a car accident.[105] In the same way, no social allocation is given to a family after the delivery of a non alive and\or non viable child.[106] Finally, as the law currently stands, an unborn child carried to full term by its mother can be destroyed through

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[102] *Montreal Tramways Co. v. Léveillé* [1933] S.C.R. 456. It bears mentioning that in a more recent case, the Supreme Court precised that there could be no analogy between a child's action for prenatal negligence against a third-party tortfeasor, on the one hand, and against his or her mother, on the other. Thereby, a mother cannot be held liable in tort for damages to her child arising from a prenatal negligent act which injured her foetus before it has been born alive and viable: *Dobson (Litigation Guardian of) v. Dobson*, [1999] 2 S.C.R. 753.

[103] *Winnipeg v. D.F.G.*, *supra* note 97 at par. [14].

[104] *Ibid.* at par. [14]. It has to be noted that in the area of family law, Canadian provincial legislation, especially child protection legislation, may sometimes include unborn children within their definition of "child". See e.g. the New Brunswick *Family Services Act*, S.N.B. 1980, c. F-2.2, s.1(g). Some courts have also found that the unborn foetus is a "child" for the purposes of family law regulations: *Re Children's Aid Society of City Belleville and T.*, (1987) 59 O.R. (2d) 204 and *Re Children's Aid Society for the District of Kenora and J.L.* (1981), 134 D.L.R. (3d) 249, but some others have reached precisely the opposite conclusion: *Re Baby R* (1988) 15 R.F.L. (3d) 225 (B.C.S.C.) and *New Brunswick (Minister of Health and Community Services) v. N.H. (Litigation guardian of)*, [1996] N.B.J. No. 660. One can however admit that a foetus is not a child for the purposes of provincial child protection laws, at least, as long as it remains within the mother. For discussion of the aforementioned cases, see S. Martin and M. Coleman, "Judicial Intervention in Pregnancy" (1995) 40 McGill L.J. 947 at 950-71.

[105] See e.g. in Quebec: Assurance-Automobile – 109, [1997] C.A.S.691 (C.A.S), AZ-97051160.

[106] See e.g. in Quebec: Aide sociale – 2, [1993] C.A.S. 30 (C.A.S.), AZ-93051007.

negligent conduct but, other than damages to the mother, there is no separate award of damages for loss of the foetus.[107]

Such an overview would not be complete without looking at abortion policies and criminal law. In Canada, abortion has legally been allowed at any stage of the pregnancy since the Supreme Court's decision in *R. v. Morgentaler* in 1988.[108] Save for Subsection 238(1) of the *Criminal Code*,[109] which deals with killing an unborn child in the act of birth,[110] Canada has not fixed a point in time, following conception, after which the killing of a foetus is only allowed in limited circumstances, such as, for example, to save the life of the mother.[111] In 1987, the Saskatchewan Court of Appeal was asked to rule that abortions violated the foetus's right to life and equality under the *Canadian Charter of Rights and Freedoms.*[112,113] The Court stated that a foetus was *not a person* capable of claiming rights under the *Charter* and concluded that a

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[107] See *Martin v. Mineral Springs Hospital*, 2001 ABQB 58.

[108] *R. v. Morgentaler*, [1988] 1 S.C.R. 30. Under the provisions of the *Criminal Code* (R.S.C. 1985, c. C-46, s. 251), abortion was permitted if the continuation of the pregnancy would or would be likely to endanger the woman's life or health. These provisions also imposed some restrictions: an abortion was required to be carried out by a qualified medical practitioner in an accredited or approved hospital that had a therapeutic abortion committee comprised of no fewer than three qualified medical practitioners. In January 1988, the Supreme Court of Canada ruled that Section 251 of the *Criminal Code* was unconstitutional because it violated Section 7 of the *Canadian Charter of Rights and Freedoms* (*infra*, note 113) which guarantees the right to "life, liberty, and security of the person". It has to be stressed that in this decision, the Supreme Court held that it did not need to rule on whether the foetus was a person to decide the case. Therefore, the issue of when personhood begins was carefully avoided in *R. v. Morgentaler*: see E.W. Keyserlingk, *Sanctity of Life or Quality of Life, supra* note 20 at 93.

[109] *Criminal Code*, R.S.C. 1985, c. C-46, s. 238(1).

[110] "In the act of birth" means "once contractions are progressing". See *R. v. Drummond,* [1996] 112 C.C.C. (3d) 481 (Ont. Ct. Prov. Div.): on-line at: LexisNexis, 1996 ONT. C.J.P. Lexis 4 at 6

[111] *Ibid.* at 4.

[112] *Borowski v. Canada (Attorney General)*, [1987] 4. W.W.R. 385, 33 C.C.C. (3d) 402 (Sask. C.A.). Borowski's case never made it to the Supreme Court as the decision in *R. v. Morgentaler* made the issue in Borowski's appeal moot.

[113] *Canadian Charter of Rights and Freedoms*, Part I of the *Constitution Act, 1982 (79)*, enacted as Scheduled B to the *Canada Act 1982* (U.K.), 1982, c. 11 [hereinafter: the *Charter*].

foetus was not included within the definition of "everyone" in section 7,[114] or "every individual" in section 15(1)[115] of the *Charter*. In *Tremblay v. Daigle*,[116] the Supreme Court held that the unborn child did not have a right to life under the *Quebec Charter of Human Rights and Freedoms*,[117] which provides that every human being has a right to life and that an unborn child was not a human being within that *Quebec Charter*. Thus, the court ruled that since the unborn foetus has no legal existence, a third party could not intervene in a woman's decision to abort in order to protect the rights of the unborn.

The issue of the legal status of the foetus in criminal law has moved beyond abortion. The *Criminal Code* expressly defines a "human being" as someone who has completely proceeded, in a living state, from the body of its mother.[118] Consequently, in *R. v. Sullivan*,[119] the Supreme Court of Canada held that a foetus in the process of being born was not a "person" for the purposes of a prohibition against criminal

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[114] Section 7 of the *Charter* (*supra* note 113) provides: "Everyone has the right to life, liberty and security of the person and the right not to be deprived thereof except in accordance with the principles of fundamental justice."

[115] Section 15(1) of the *Charter* (*supra* note 113) provides: "Every individual is equal before and under the law and has the right to the equal protection and equal benefit of the law without discrimination and, in particular, without discrimination based on race, national or ethnic origin, colour, religion, sex, age or mental or physical disability."

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

[117] *Quebec Charter of Human Rights and Freedoms*, L.R.Q. c. C-12 [hereinafter: *Quebec Charter*].

[118] *Criminal Code*, R.S.C. 1985, c. C-46, s. 223(1), which provides that "A child becomes a human being within the meaning of this Act when it has completely proceeded, in a living state, from the body of its mother, whether or not (a) it has breathed; (b) it has an independent circulation; or (c) the navel string is severed."

[119] *R. v. Sullivan*, [1991] 1 S.C.R. 489. In that case, two midwives assisting a home birth were unable to complete a delivery. The mother had been transported to a hospital but, in the meantime, the child had asphyxiated in the birth canal. The midwives had been charged with criminal negligence causing the death of the foetus and criminal negligence causing bodily harm to the mother. An acquittal was directed on both counts on the grounds that the foetus was not a human being under the *Criminal Code* and that it was not a part of the mother.

negligence causing the death of a person. In that case, the court strongly reaffirmed the "born alive rule".

In 1996, *R. v. Drummond*[120] involved a pregnant woman in Ontario, Brenda Drummond, who tried to kill herself or her foetus by discharging a pellet gun into her vagina. The baby was born alive a few days later. Attempted murder charges were brought under subsection 223(2) of the *Criminal Code*.[121] In this case, defense lawyers were saying that this was merely a failed abortion which, as explained above, is no longer a crime in Canada. The provincial court concluded that the charge could not be supported as the foetus was not a person for the purposes of the *Criminal Code*.[122]

2. United States

In the United States, abortion and the status of foetuses in law has been perhaps the most enduring political issue of the last thirty years.[123]

In 1973, in *Roe v. Wade*, in the context of abortion, the majority of the Supreme Court held that a foetus was not a person within the language and meaning of the fourteenth

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[120] *R. v. Drummond, supra* note 110.

[121] *Criminal Code*, R.S.C. 1985, c. C-46, s. 223(2), which says that "[a] person commits homicide when he causes injury to a child before or during its birth as a result of which the child dies after becoming an human being."

[122] It has to be noted that in another case, *R. v. Prince*, the accused – who had stabbed a woman who was six months pregnant – was convicted of attempted murder of the woman and manslaughter of the child under subsection 223(2) of the *Criminal Code*, because in this case, the foetus had died a few minutes after birth: *R. v. Prince*, [1986] 2 S.C.R. 480, 33 D.L.R. (4th) 724.

[123] C. Feasby and S. Chambers, "Case comment and note: Comments on Winnipeg Child and Family Services (Northwest Area) v. D.F.G." (1998) 36 Alberta L. Rev. 707 at 707.

Amendment.[124] *Roe v. Wade* implies that "live-birth" is both a necessary and sufficient condition for the existence of human life to which criminal laws might attach. However, while avoiding the question of whether life begins at conception, the Court acknowledged that at some point the state may have compelling interest in the protection of human life and therefore of the unborn child. The Court established that point at *viability.*[125] Following *Roe v. Wade*, the Court reviewed the constitutionality of various state statutes seeking to regulate abortion.[126] In a nutshell, a state may regulate abortion throughout the pregnancy and pre-viability as long as the regulation does not impose an "undue burden" on a woman's right to terminate her pregnancy.[127] In this respect, abortion is available on demand during the first and, to a somewhat lesser extent, second trimester in the United States.[128] After foetal viability, the states may proscribe abortion unless it is necessary to save the life or preserve the health of the mother.[129] Consequently, as stated by Gross, "at the beginning of the third trimester or age of viability (whichever comes first) the foetus gains a measure of legal

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[124] *Roe v. Wade*, 410 U.S. 113, 93 S. Ct 705, 35 L.Ed.2d 147; 1973 U.S.

[125] It must be stressed that according to the Supreme Court, after viability, there is "foetal life", not a "person". What line exactly viability is supposed to mark remains unclear.

[126] For discussion of the cases pertaining to abortion regulations, see M. De Rosa, "Partial-birth abortion: Crime or Protected Right?" (2002) 16 St. John's J.L. Comm. 199. The Supreme Court upheld the constitutionality of many of the statutes regulating abortion. It has to be noted that in each case, the Supreme Court reaffirmed the "three-part holding" in *Roe v. Wade*, namely: "(1) the right of the woman to choose to have an abortion before viability without undue interference from the state, (2) the power of the State to restrict abortion after viability provided there are adequate exceptions for the health and life of the mother, and (3) the legitimate state interests in protecting the life of the foetus and the health of the mother exist at the beginning of the pregnancy and continue throughout the duration of the pregnancy.": *ibid.* at 204.

[127] In *Planned Parenthood of Southeastern Pa. v. Casey*, 505 U.S. 833, 120 L. Ed. 2d 674, 112 S. Ct. 2791; 1992 U.S. the plurality rejected the trimester framework adopted in *Roe v. Wade* and adopted a so-called "undue burden standard". Under this new standard, an undue burden exists when the purpose or effect of a statute is to place a substantial obstacle in the path of a woman seeking an abortion before the foetus attains viability: *ibid.* at 204-5.

[128] M.L. Gross, "Abortion and Neonaticide", *supra* note 24 at 208.

[129] In some states, a foetus may also be aborted late in the pregnancy if it is so "grossly deformed or impaired that it is not judged to be in the foetus's best interests to continue to live", but this is a minority opinion: *ibid.* at 209.

personhood, recognition and protection under American law that is unprecedented among most other developed countries".[130]

However, it has to be stressed that despite *Roe v. Wade*, the legal status of the foetus with respect to personhood varies widely from state to state. Twenty-four states criminalize actions against the foetus in some manner, the rest do not.[131]

There is also an increasing recognition of the foetus as a person in American tort law. In the majority of American jurisdictions, if a child is stillborn but survived an injury *in utero* to reach the point of viability, a wrongful death action may be maintained.[132] In other words, most American states allow wrongful death actions for a stillbirth, renouncing the "live-birth" requirement and focusing instead on the point of viability.

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[130] *Ibid.* at 208. Since 1998, the movement toward a full recognition of the foetus as a person has dramatically increased in the US. For a presentation of abortion regulations or numerous anti-choice measures enacted in each American state, see the National Abortion and Reproduction Rights Action League, "Who decides? A State by State Review of Abortion and Reproductive Rights", 12th ed. (2003): http://www.naral.org/mediaresources/publications.html#try (accessed June 2003).

[131] In summary, some state legislatures now define murder or homicide to include the killing of a foetus. This is the case in Indiana, which considers as murder the "knowingly or intentionally killing a foetus that has attained viability". Minnesota created a separate chapter in its criminal code entitled "Crimes against unborn children". Utah law stipulates that a person commits criminal homicide if he causes the death of another human being, "including an unborn child". Several states have refused to regard foetuses as persons for the purposes of their murder laws, but have chosen to penalize assaults against pregnant women that result in either miscarriage or injury to the foetus. Alternatively, several jurisdictions still exclude foetuses from their murder statutes and refer to the long-standing common-law "born alive" rule. For discussion of these legislatures and references, see "What We Talk About When We Talk About Persons", *supra* note 95 at 1755-60. In Iowa, criminal law makes illegal certain acts related to abortion procedures. It prohibits the crime of "feticide". Feticide is defined as the crime of causing the death of a foetus, after the second trimester of the pregnancy, by intentionally terminating the pregnancy "with the knowledge and voluntary consent of the pregnant person". It is thus a prohibition against abortion after the second trimester of the pregnancy. See J.M. Steffens, "The 'Peculiar' Being: The Rights of an Unborn Child in Iowa" (2002) 88 Iowa L. Rev. 217 at 228-9.

[132] *Nealis v. Baird,* 1999 OK 98, 996 P.2d 438; 1999 Okla. at par. [22]. See also F. Marouf, "Wrongful death: Oklahoma Supreme Court replaces viability standard with "live birth" standard" (2000) 28 (1) Journal of Law, Medicine & Ethics 8890: http://www.aslme.org/news/jlme/28.1d.html (accessed May 2003).

But is a wrongful death action similarly permissible where the child is born alive, but prior to attaining viability? In 1999, the Oklahoma Supreme Court held in *Nealis v. Baird* that a claim may be brought under Oklahoma's wrongful death statute on behalf of a non-viable foetus born alive.[133] Thus, this Court held a non-viable foetus as a legal person for the purpose of a wrongful death claim, holding that "once live birth occurs, the debate over whether the foetus is or is not a person ends" and the live born child attains the legal status of "person".[134]

Therefore, when a child's death is caused by prenatal injury inflicted at any time during gestation, the American trend is to recognize a foetus as a legal person when it is subsequently born alive *or* viable. It has to be noted that some states have gone further, holding that a wrongful death action may also be brought on behalf of a stillborn and non-viable foetus.[135]

In any case, it is clear that American law (either civil, common or criminal law) has moved over the years in the direction of increased respect and legal protection of foetal life.

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[133] *Nealis v. Baird, supra* note 132. In this case, Mr. And Mrs. Nealis sought recovery from three physicians for the wrongful death of their prematurely born child.

[134] *Ibid.* at par. [36].

[135] In 1995, the Supreme Court of West Virginia held that a wrongful death action can be brought on behalf of a stillborn and non viable foetus killed *in utero* in an automobile accident at approximately eighteen to twenty-two weeks of gestation: *Farley v. Sartin*, 195 W.Va 671, 466 S.E. 2d 522; 1995 W. Va. Two other states have reached the same conclusion, basing their decisions upon specific statutory language: *Wiersma v. Maple Leaf Farms*, 1996 SD 16, 543 N.W. 2d 787; *Connor v. Monkem Co., Inc.,* 898 S.W. 2d 89; 1995 Mo. However, the majority of American jurisdictions which have considered recognition of a cause of action for a non-viable stillborn child have held that no such cause of action exists. See other references in *Nealis v. Baird, supra* note 132 at par. [27].

C. The born alive and viable rule: the twists and turns of a fuzzy gradient

One might expect that the legal criteria of personhood and thereby the consequential ascription of rights would be unequivocal and stable. However, this is not the case. The apparent simplicity of the "born alive and viable" rule is misleading. In this respect, there are a few specific points that must be elucidated.

1. Confusing discrepancies between the states and different bodies of law

Different courts have approached the determination of foetal personhood in different ways and a deep theoretical divide remains.[136] In the United States particularly, significant discrepancies exist between individual states. As mentioned above, some of them, through statutory interpretation, have adopted a "born alive *or* viable" rule or have even enacted statutes that expressly afford a significant measure of legal personhood to non-viable foetuses *before birth*. Moreover, in the same state or country, foetuses may be regarded as persons in one area of law but not in another. In a global perspective, such ambivalence regarding the beginning of legal personhood is confusing.

[136] See "What We Talk About When We Talk About Persons, *supra* note 95 at 1758.

2. *What constitutes "live-birth" and "viability"?*

There are major concerns about the interpretation of the "born alive and/or viable rule". What does it mean to be born "alive" and "viable"? It is undeniably true that an answer to this question could theoretically have an impact on the legal status of very defective neonates: when does a foetus become a very defective neonate, alive and viable and, therefore, a legal person who is entitled to a right to life and a right to be treated? There can be no doubt that what constitutes viability and even live-birth for extremely premature infants is a critical question. The answer may depend on the definitions given to those criteria.

2.1. Live-birth

In Canada, the aforementioned decisions provide little guidance on the issue. As long ago as 1927, in a civil case, the Superior Court of Quebec stated that:

> Un enfant doit être considéré comme ayant vécu [...] lorsque après sa sortie du sein de la mère, il a respiré d'une façon complète, d'une façon naturelle. C'est par la respiration complète que la circulation du sang s'établit dans les poumons et que l'enfant vit de sa propre vie. Dans ces conditions, aux yeux de la loi, il vit civilement, car la première fonction qui s'exécute chez l'enfant qui vient de naître, c'est la respiration complète qui constitue la vie.[137]

In other words, to be *alive* and to become a legal person in the Quebec civil law, the child must completely emerge from the birth canal and breathe "in a complete and natural way". One must admit that such a definition has become indefensible with

[137] *Allard v. Monette* [1927] 66 C.S. 291 at 293.

regard to advances in medical technology. It is well-known that very defective neonates may not breathe at birth unless they are medically helped to do so.

Consequently, the definition of "live-birth" has been qualified. In Canadian criminal law, for example, a foetus becomes a human being when it has completely proceeded, in a living state, from the body of its mother, regardless of whether or not it has breathed.[138] Thus, respiration is no more the only relevant vital sign. However, the *Criminal Code* gives no definition of what may constitute a "living state". Such a definition is not given in other bodies of law either.

In Quebec, civil decisions have notably referred to the newborn's APGAR score[139] to determine whether the infant is born alive and has become a "legal person".[140] In this respect, the presence of any vital sign might not be sufficient to constitute a live-birth.[141] In practice, to determine if the child is born alive, courts will rely on medical evidence. Yet, there is no scientific consensus on this issue: some studies defined a stillborn as any infant with a one-minute Apgar score of zero, while some other studies defines "a sub-group of 'stillborn' who had shown 'recent signs of life' suggesting a

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[138] See *supra* note 118.

[139] The APGAR score, devised in 1952 by Virginia Apgar, is a numerical expression of the medical condition of a newborn. Quickly after delivery, Appearance (color), Pulse (heartbeat), Grimace (reflex), Activity (muscle tone), and Respiration (breathing) are assessed. Points are given for each sign. A total score of 7-10 is considered normal, while 4-7 might require some resuscitative measures, and a baby with an Apgar score of 3 and below requires immediate resuscitation or might be considered stillborn.

[140] See e.g.: Assurance-Automobile – 109, *supra* note 105.

[141] In Assurance Automobile – 109 (*supra*, note 105), the Apgar score of the neonate was zero. According to the court, such a score confirms a stillbirth. But what would be the situation with a score between 1 and 3? What vital sign would be relevant enough to constitute a live-birth?

better potential for resuscitation".[142] Therefore, live-birth may raise complex evidentiary problems.[143]

In the United States, it has been argued that the definition of "live-birth" is "fairly settled".[144] In general, state statutes are similar to that relied upon by the Florida Supreme Court in *Re T.A.C.P.*, which defines "live-birth" as:

> The complete expulsion or extraction of a product of human conception from its mother, irrespective of the duration of pregnancy, which after such expulsion, breathes or shows any other evidence of life such as beating of the heart, pulsation of the umbilical cord, and definite movement of the voluntary muscles, whether or not the umbilical cord has been cut or the placenta is attached.[145]

However, such a definition is not unequivocal. As stated by the Court of Appeal of Michigan, "to conclude that one is 'alive' if there is present 'some evidence of life' is a tautology and begs the question of what constitutes 'life' or 'being alive'".[146] According to this court, such a definition provides utterly no legal guidance. In any case, one has to admit that there is no precise definition of what constitutes "some evidence of life".

Finally, it has to be noted that the live-birth rule is also criticized by those who support the existence of foetal rights before live birth. They argue that the "live birth" rule is a

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[142] R.J. Boyle and N. McIntosh, "Ethical considerations in neonatal resuscitation: clinical and research issues" (2001) 6 Semin Neonatol 261 at 263.

[143] See for example: *La Reine c. Lucas*, (1999-12-10) QCCQ 110-01-002768-989: http://www.canlii.org/qc/jug/qccq/1999/1999qccq199.html (accessed August 2003). In this case, Nathalie Lucas had been charged with infanticide. The Court of Quebec concluded that the live-birth of the newborn had not been proved. Consequently, Nathalie Lucas was acquitted.

[144] M.A. Hughes, "Life, Death and the Law: Should the Anencephalic Newborn Be A Source for Organ Donation?" (1995) Regent University Law Review 299 at 307.

[145] *Ibid.* quoting *In re T.A.C.P.*, 609 So.2d 588; 1992 Fla.

[146] *People v. Selwa*, 214 Mich. App. 451; 543 N.W.2d 321; 1995 Mich. App. at 462 and *Thomas v. Stubbs*, 218 Mich. App. 46, 553 N.W.2d 634, 1996 Mich. App. at 51.

legal anachronism based on rudimentary medical knowledge and that it should no longer be followed in a world where "techniques like real time ultrasound, foetal heart monitor, and fetoscopy can clearly show that a foetus is alive and has been or will be injured by the conduct of another".[147] Thus, according to such a theory, live-birth should not be a necessary condition for the ascription of rights to the foetus.

The current debate on partial-birth abortions[148] in the United States may also illustrate this theory and the actual limitations of the "born alive rule". Theoretically, legal birth may only occur if a baby completely emerges from the uterus and shows signs of life. In partial-birth abortion procedures, the living foetus has not completely emerged from the birth canal. Consequently, it is not yet a legal person pursuant to the "born alive rule". In response to this issue, both Congress and state legislatures took action by proposing bans on this abortion procedure.[149] While previously vetoed by former President Clinton, a national ban on partial-birth abortion is now supported by President Bush and is likely to be enacted soon.[150] In any case, such bans clearly show

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[147] In Canada, see, for example, Major J. and Sopinka J., dissenting in *Winnipeg v. D.F.G*, *supra* note 97 at par. [109]. For a strong critique of this dissenting opinion, see F.C. DeCoste, *supra* note 62 and C. McIntosh, "Conceiving Fetal Abuse" (1998) 15 Can. J. Fam. L. 178 at 212-3.

[148] "Partial-birth abortion is a legal term for what is medically referred to as 'intact dilation and extraction' or 'intact D&X'. It involves the destruction of the fetus during the birth process. According to the American College of Obstetricians and Gynecologists, the procedure contains four elements: (1) over the course of several days the cervix is deliberately dilated; (2) with instruments, the fetus is converted to breech position; (3) in breech position the fetus is, except for the head, extracted from the uterus and into the birth canal; and (4) the intracranial contents of the fetus are partially extracted which has the effect of vaginally delivering an "intact" but dead fetus": M. De Rosa, *supra* note 126 at 207-8.

[149] Thirty states have attempted to regulate abortion in the form of a partial-birth abortion ban, except when the procedure is necessary to save the mother's life. For discussion of these regulations and their constitutionality, see M. De Rosa, *supra* note 126.

[150] CNN.com, "Partial-birth abortion ban passes House: Bush supports legislation", June 5, 2003: http://www.cnn.com/2003/ALLPOLITICS/06/04/congress.abortion.ap/ (accessed June 2003).

how much an increasing legal protection afforded to the foetus may affect the significance and the impact of the traditional live-birth rule.

2.2. Viability

Live infants are not necessarily viable. The definition of this second criterion, namely 'viability', raises even more difficulties than the meaning of "live-birth". In 1997, Deleury and Goubeau still describe the beginning of legal personhood in Quebec civil law in these words:

> [l'] enfant mort-né, de même que l'enfant né vivant, mais dont la conformation ne lui permet pas de survivre (malformations qui rendent la mort inéluctable, enfant dont les organes sont insuffisamment développés et qui ne peut avoir de vie indépendante, parce que né trop prématurément) ne sont pas des personnes aux yeux du droit.[151]

In that perspective, very defective neonates, especially very premature babies, whose condition is not compatible with life under the current medical knowledge, are not legal persons and thus, simply do not exist as persons in civil law.

This criterion of 'viability' has been criticized. It has been described as a slippery and moving concept,[152] not the least because viability may depend on the medical care available to the pregnant woman and her infant.[153] Thus, it becomes an ambiguous gradient: its definition will change "if we ask whether we mean viability in an

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[151] E. Deleury and D. Goubeau, *Le droit des personnes physiques* (Cowansville: Yvon Blais, 1997) at 9.
[152] T. H. Murray, "Moral Obligations to the Not-Yet Born: The Fetus as Patient" in E. Boetzkes and W.J. Waluchow, eds., *Readings in Health Care Ethics* (Ontario: Broadview Press Ltd, 2000) at 330, and M.A. Warren, *supra* note 23 at 272.
[153] M.A. Warren, *supra* note 23 at 272.

advanced neonatal ICU or viability in a remote rural county with limited medical resources".[154] Moreover, as our ability to save more premature newborns improves, the age of viability is reached earlier.[155]

Viability requires the capacity for sustained life outside the mother's womb (albeit artificial aid) rather than mere momentary survival.[156] The assessment of such a capacity may be extremely difficult. Prognosis for extremely premature infants is often highly uncertain and raises a complex matter of medical evaluation.[157] Moreover, the assessment of viability is influenced, if not prescribed, by medical professional guidelines, statistical survival rates and practices. The World Health Organisation, for instance, defined the perinatal period as commencing at 22 completed weeks of gestation. Infants born at 22 to 28 weeks of gestation have thus been termed as having "threshold viability".[158] According to the International Guidelines for Neonatal Resuscitation (2000), infants with confirmed gestation of less than 23 weeks or birth weight of less than 400 grams may be considered as not viable. Therefore, the initiation of resuscitation in the delivery room for such premature infants is not

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[154] D. Hope, "The Hand as Emblem of Human Identity: A Solution To The Abortion Controversy Based on Science and Reason" (2001) 32 U. Tol. L. Rev. 205 at 211.

[155] In 1973, an American leading obstetric test stated that infants generally were not viable below twenty-eight weeks of gestational age and 1000 grams of weight. This lower limit is clearly obsolete. See *supra* note 5 and N.K. Rhoden, "The New Neonatal Dilemma: Live Births from Late Abortions" (1984) 72 Geo. L.J. 1451 at 1465, and T. H. Murray, *supra* note 152 at 330.

[156] N.K. Rhoden, *supra* note 155 at 1476. For example, viability was defined as "the ability to sustain life", or "the moment when the unborn child can survive independently of its mother" in *Nealis v. Baird*, *supra* note 132 at par. [21, 41].

[157] See *supra* note 13.

[158] World Health Organisation, *Managing Complications in Pregnancy and Childbirth. A Guide for Midwives and Doctors* (WHO, 2000) http://www.who.int/reproductive-health/impac/ Symptoms/Vaginal_bleeding_early_S7_S16.html (accessed August 2003) in Section 2 "Symptoms", in the chapter entitled "Vaginal bleeding in early pregnancy", in Box X-1.

"appropriate".[159] In Canada and the United States, the same limit of viability has been adopted with caution and qualification by the CPS[160] and the AAP.[161] It is worth noting that different limits of viability have been adopted in other countries.[162]

In any case, beyond professional and ethical guidelines, clinical practices themselves have a significant impact on the concept of viability. In this respect, significant discrepancies exist within countries and even within the same medical institutions. There is no agreement on what may constitute viability. In deciding to attempt resuscitation (or not) of a neonate at birth, one physician may regard an infant as not viable unless his or her chances of survival are fifty percent, while another may believe that a thirty-, twenty-, or even ten-percent chance will suffice.[163]

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[159] S. Niermeyer, ed., "International Guidelines for Neonatal Resuscitation: An Excerpt From the Guidelines 2000 for Cardiopulmonary Resuscitation and Emergency Cardiovascular Care: International Consensus on Science" (2000) 106 (3) Pediatrics: http://www.pediatrics.org/cgi/content/full/106/3/e29 (accessed May 2003) at 13-4.

[160] As mentioned above (*supra* Part II, Section B, 3.), the CPS states that before 22 weeks of gestation, foetuses/infants are not viable and should be given only compassionate palliative care. However, "the neonatologist may decide to provide active treatment for apparently viable infants whose gestational age may have been underestimated". See CPS, "Management of the woman with threatened birth of an infant of extremely low gestational age", *supra* note 70.

[161] AAP, "Perinatal Care at the Threshold of Viability", *supra* note 72, referring to D. Braner *et al.*, eds., *Textbook of Neonatal Resuscitation* (ed. 4) (Elk Grove Village: Amer Academy of Pediatrics, 2000). It may be noted that in 1973, in *Roe v. Wade* (*supra* note 124), the Supreme Court of the United States suggested that viability occurs at twenty-four to twenty-eight weeks of gestation, recognizing, however, that each individual physician had to determine when viability is attained in each individual case: see J.L. Lenow, "The Fetus as a Patient: Emerging Rights as a Person?" (1983) 9 Am. J. L. and Med. 1 at 11.

[162] For instance, in Switzerland, according to the guidelines issued by the Swiss Society of Neonatology, the standard limit of viability is 24 weeks of gestation. Before that time, infants should be provided with comfort care only: Swiss Society of Neonatology, "Recommendations pour la prise en charge des prématurés à la limite de la viabilité (22-26 semaines de gestation)": http://www.neonet.ch/gestationsalter-f.doc (accessed May 2003). In France and Japan, the ability to sustain life at birth is defined as at least 22 weeks of gestation and minimum weight of 500 grams: see CCNE, *supra* note 76 at 7; M. Dehan *et al.* (Fédération Nationale des Pédiatres Néonatologistes), *supra* note 77 at 417, and J. Bregman, *supra* note 11 referring to the Japanese Eugenics Protection Law at 675. It is worth noting that any reference to malformations incompatible with life (as mentioned by Deleury and Goubeau in Quebec, *supra* note 151) have been abandoned in France: see J.C. Ropert, "Les dilemmes éthiques", *supra* note 79 at 47s.

[163] N.K. Rhoden, *supra* note 155 at 1494.

In this respect, it must be stressed that statistics and predictions of survival in very defective newborns, relied upon by neonatologists and the aforementioned guidelines to define the limits of "viability", must be viewed with caution. Indeed, statistics cannot truthfully reflect the real impact of disparate clinical practices and other factors on the survival rates of very defective infants.[164]

Finally, it must be stressed that, in any case, the decision to treat or not to treat very defective neonates goes quite beyond the controversial definition of the concept of "viability". Such a decision is also influenced by criteria that are not related to survival rates and medical prognosis.

The best explicit example is certainly found in Denmark where the Danish Council of Ethics has issued a protocol recommending the aggressive treatment of infants younger than 24 or 25 weeks of gestation in exceptional circumstances only. However, for the Danish Council, this threshold of viability "may be overridden both by parents wishing to care for a child that fails to meet the criterion [of maturity] or by parents requesting to withhold treatment from a newborn that meets the threshold

[164] Survival rates are influenced by such factors as prenatal use of steroids, presence of fatal compromise, accuracy of gestational age, gender, race: P.J. Van Reempts and K.J. Van Acker, *supra* note 1 at 226. Survival rates are also influenced by local treatment policies in particular medical institutions: in one neonatal intensive care unit, a standard treatment policy can discourage any attempt to resuscitate a 23 weeks old neonate while in another hospital, such an attempt would be the rule. Moreover, Mahowald clearly describes the limitations of survival statistics by noting: "I think for example of a infant born with heart defects so grave that none similarly afflicted had ever been known to survive, whose recovery after surgery changed the mortality rate applicable to others...": M.B. Mahowald, "Decisions Regarding Disabled Newborns" in E. Boetzkes and W.J. Waluchow, eds., *Readings in Health Care Ethics* (Ontario: Broadview Press Ltd, 2000) at 336.

requirement".[165] Thus, a decision to provide aggressive treatment may also be a function of the care a child can expect to receive from his or her parents and as such the threshold of viability may lose all significance if the parents are unwilling or unable to provide the intensive care a preterm infant requires.[166]

Such considerations are not absent in Canada. According to the CPS, at 22 completed weeks of gestation, neonates should be offered only compassionate palliative care because "accounts of survival are mainly anecdotal". However, active treatment could be started "at the request of fully informed parents".[167]

This demonstrates that viability is an nebulous concept that can be interpreted and qualified in many different ways. Thus, it is disturbing to think that legal personhood and a decision to treat or not to treat very defective neonates could depend upon such versatile interpretations, made by individual physicians (and even parents) in the framework of disparate clinical practices. I maintain, as Varga did, that "viability is a measure of the sophistication of our neonatal life-support systems. Humanity remains the same, but viability changes. Viability measures medical technology, not one's humanity."[168]

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[165] For discussion of this protocol and references, see M.L. Gross, "Avoiding anomalous newborns: preemptive abortion, treatment thresholds and the case of Baby Messenger" (2000) 26 Journal of Medical Ethics 242 [hereinafter: M.L. Gross, "Avoiding anomalous newborns"].
[166] *Ibid.* at 243.
[167] CPS, "Management of the woman with threatened birth of an infant of extremely low gestational age", *supra* note 70.
[168] A. Varga, *The Main Issues in Bioethics* (New-York: Paulist Press, 1984) at 62.

3. Consequences

The overall picture shows that there are major concerns about the interpretation of the "born alive and viable rule". This rule has been qualified and manipulated in different ways in different bodies of law, which has led to significant discrepancies. As mentioned above, some jurisdictions have even come to admitting the legal personhood of unborn or stillborn foetuses when "viable".[169]

Thus, live-birth and even birth itself are not always necessary pre-conditions to legal personhood. As a result, it has become difficult to determinate when and whether birth, live-birth and viability are necessary, alternative or cumulative conditions of legal personhood.[170]

Moreover, this confusion has blurred the distinction between the status of late-term foetuses and that of neonates. For instance, if legal personhood may depend upon "viability" only, it appears that there is little difference between the status of a late-term foetus and a neonate. Therefore, the "viability" criterion, depending once more on how it is defined, can result in a stronger recognition of the legal personhood of healthy late-term and thus viable foetuses than of very defective neonates, whose medical condition does not seem compatible with life.

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[169] See *supra* Part III, Section B, 2.

[170] Henceforth, I will thus refer to the "born alive and/or viable rule".

However, such perspectives and consequences have never been taken into serious consideration by North-American courts. On the contrary, it will be demonstrated below that the legal personhood of very defective neonates has rarely been openly challenged upon these (or any other) grounds.

D. The legal status of very defective neonates

I submit that the legal personhood of very defective neonates could be challenged on two different grounds.

First, as demonstrated above, the "born alive and/or viable rule" has been manipulated in different ways to recognize or, conversely, to negate the legal personhood of foetuses. The legal significance of birth itself has been challenged in the context of partial birth abortion and suggests that the passage from the state of foetus (that is from a "non-person" status) to that of a very defective neonate (who must be considered as a person) remains delicate. In these circumstances, there is no reason to preclude the use and the manipulation of the "live-birth" and "viability" criteria to negate the personhood of very defective neonates themselves in certain circumstances. Certainly, the "born alive and/or viable rule" has systematically been used or at least mentioned when the legal status of unborn foetuses was at stake in abortion or prenatal negligence cases. Conversely, the legal personhood of neonates themselves who have not been endangered or hurt by third parties before their birth but whose prematurity or defective condition is threatening their very ability to survive after birth, that is their

viability and even live-birth, has rarely been discussed in the courts' decisions, in particular when it has come to assessing neonates' right to life and their right to be treated.[171]

Second, the legal personhood of very defective neonates could also be called into question under considerations that are not directly linked to the "born alive and/or viable" rule but to the criteria described in the moral personhood theories presented above in Part II. To delineate the beginning of legal personhood on the basis of such criteria (such as the absence of cognitive functions or other capacities attached to the moral notion of person) would obviously imply a dramatic change in the traditional perception of this legal concept. As demonstrated below, North-American courts have not followed this path either.

Thus, legal doctrine and jurisprudence from North-America demonstrate that the legal personhood of very defective neonates has not been successfully challenged on either of the above grounds. A concise selection of judicial decisions, statutes and legal comments elucidates the North-American perception of the legal personhood of these neonates. Despite a few exceptions, courts have never considered the demands and limitations of a duty to treat very defective neonates or their right to life using criteria

[171] It has to be stressed that very few cases pertaining to non-treatment decisions made on behalf of defective infants include some direct references to their legal personhood. Moreover, in Canada, most cases have involved older infants (and adults) and not neonates. In these circumstances, "live-birth" and/or "viability" immediately after birth as conditions of legal personhood were rarely considered. Thus, there is less guidance in this respect when life-sustaining treatment is *initially* denied at birth for reasons related to the non-viability of a very defective neonate.

related to their legal personhood. Instead, courts have mainly focused on the "best interests" of infants and the "medical standards of care".

1. Canada

The Canadian case *Re Enfant Maude Goyette*[172] is particularly relevant concerning the matter of personhood.

In this case, the Quebec Superior Court firstly referred to the article 19 of the *Civil Code of Lower-Canada* (*C.C.L.C.*) which provided that the "human person is inviolable".[173] It also mentioned that, pursuant to art. 18 *C.C.L.C.* (current art. 1 *C.c.Q.*), every human being possesses "juridical personality".[174] Noting that the *Civil Code* did not define the notion of "human being", the Court stated:

> Il y a une présomption que tout être issu d'humains est humain et possède la personnalité juridique. Mais cette présomption est-elle irréfutable? Si, par hypothèse, il était positivement démontré qu'un être issu d'humains, n'est humain qu'en apparence, ne pourrait-on lui nier ou lui retirer la personnalité juridique et, en mettant fin à son existence, ne commettre aucun homicide? Cela suppose deux choses: d'abord l'acceptation d'une définition de l'être humain; ensuite un moyen de vérifier absolument la nature humaine d'un être donné. ... *La difficulté est plutôt dans le moyen d'avoir la certitude que d'une part, le corps est assez formé ou l'est demeuré et, d'autre part, que l'esprit ou la faculté mentale est fonctionnel ou ne l'est définitivement plus.* C'est une question de fait à laquelle les équipes médicales, de concert avec les parents, apportent quotidiennement des réponses et, là-dessus, règlent leur conduite. Les cas litigieux sont destinés à être tranchés judiciairement.[175]

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[172] *In Re Enfant Maude Goyette* [1983] C.S. 429. The case of Maude Goyette involved a 26 month old baby girl born with Down Syndrome and suffering from severe cardiac defects that would have led her to her death without surgery. In this case, parents refused to consent to the surgery and the Centre des Services Sociaux du Montréal Métropolitain sought judicial authorization for the operation, which was granted by the Quebec Superior Court in 1982.

[173] A similar provision exists in the current *Civil code of Quebec (C.c.Q)* S.Q., 1991 c. 64 [hereinafter: "*Civil Code*"]. The art. 10 *C.c.Q.* provides that "every person in inviolable and is entitled to the integrity of his person."

[174] "Juridical personality" means nothing else but "legal personhood".

[175] *In Re Enfant Maude Goyette*, *supra* note 172 at 432 (emphasis added).

The Court concluded that despite her physical and mental deficiencies, Maude Goyette perfectly fulfilled the "conditions" attached to the notion of "human being" and that she consequently possessed juridical personality and the full enjoyment of civil rights.[176] Therefore, and pursuant to the *Civil Code*, the Court could then attempt to determine her best interests.

We cannot deny that in this case the legal personhood of a disabled child was at stake. It is striking to note that to determine the "humanness" of Maude Goyette, the Court referred to a famous American case (*In re Quinlan*)[177] involving a comatose, non-cognitive teenager (Karen Quinlan), lying in a chronic vegetative state and kept alive with artificial ventilation. Comparing Maude Goyette's medical status with that of Karen Quinlan, the Court concluded that there was no analogy between Karen's irrevocable loss of cognition and Maude Goyette's situation.[178] However, the "humanness" of Karen Quinlan had never been challenged by the American Court. On the contrary, the Supreme Court of New Jersey affirmed that Karen Quinlan - as a person - retained the right to have her life-sustaining treatment withdrawn on the ground of quality of life factors and not on considerations related to her legal personhood. Yet, in the case of Maude Goyette, did the Quebec Superior Court mean that, in certain circumstances, legal personhood could be lost? In any case, such an argumentation could imply that cognitive functions could be a prerequisite of legal personhood.

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[176] *Ibid.* at 433.
[177] *In re Quinlan*, 70 N.J. 10, 355 A.2d 647; 1976 N.J. cert.denied, 429 U.S. 922 (1976).
[178] *In Re Enfant Maude Goyette, supra* note 172 at 433.

It appears that *Re Enfant Maude Goyette* is a unique case where considerations relating to moral personhood – such as the presence or absence of cognitive functions described in some of the personhood theories presented above in the second part of this thesis – have been expressly linked with legal personhood, and this with no mention of the "born alive and/or viable" rule.[179] Although ambiguous in its result,[180] this attempt to confront the traditional concept of legal personhood with criteria imported from moral personhood theories was courageous and deserves full respect: it has the virtue of transparency and demonstrates that there is no clear divide between legal and moral personhood.

In 1990, the Supreme Court of Quebec did not go that far in *La Commission de Protection des Droits de la Jeunesse v. C.T and G.R. and l'Hôpital pour enfants de Montréal.*[181] In this case, the Supreme Court of Quebec focused on the future potential quality of life of a just born neonate suffering from severe congenital malformations and emphazised the concept of "dignity of the person". Referring to a precedent case, the Court stated that personhood could not be dissociated from the notion of dignity of the person.[182] In other words, the respect for a person intrinsically implies the respect

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[179] Maude Goyette was obviously alive and had had the capacity to sustain life after birth. Thus, if her legal personhood had to be called into question, the Court had to consider other criteria to determine whether she could have lost her legal personhood.

[180] The Court only concluded that Maude's medical condition was not threatening her "humanness". It did not indicate if and in what specific conditions such humanness could be lost.

[181] *La Commission de Protection des Droits de la Jeunesse v. C.T and G.R. and l'Hôpital pour enfants de Montréal*, [1990] R.J.Q. 1674 [hereinafter: "*Commission de Protection des Droits de la Jeunesse v. C.T.*"]. In this case, the parents of a neonate affected with the most severe forms of spina bifida and hydrocephalus refused to consent to any surgery. The Chief of Newborn Medicine Department at the Montreal Children's Hospital brought the case to the court, arguing that the condition left untreated would almost certainly result in the death of the child or, at least, in further serious brain damage. Therefore, in his opinion, the refusal of parents to consent to treatment was not in the child's best interests.

[182] *Ibid.* at 1680-1.

for its dignity. In the Court's decision, respect for dignity of the person seems to be defined as the recognition of the full enjoyment of fundamental rights and freedoms.[183] On no account did the Court contemplate any possibility of depriving the concerned neonate from such rights and freedoms, and thereby from her legal personhood.[184] The Court focused mainly on the best interests of the child and, considering the poor future quality of life faced by the child, it concluded that the parents' decision not to consent to the surgery was reasonable.

Most other Canadian cases related to non-treatment decisions made on behalf of infants and children have not directly commented upon the concept of legal personhood.

In 1983, a British Columbia Supreme Court decision involved a six year old boy, Stephen Dawson, who had been left severely mentally and physically impaired after contracting spinal meningitis two weeks after his premature birth.[185] The Court recognized that Stephen was *a child* in need of protection under the British Columbia Family and Child Services Act and did not challenge his legal personhood. On the

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[183] Human dignity is often presented as the foundation of human rights and liberties. However, some commentators have presented the legal right to life as resulting from humanity and human dignity, that is from the core of the human being, and not from considerations related to legal personhood. See G. Loiseau, "Le rôle de la volonté dans le régime de protection de la personne et de son corps" (1992) 37 (4) McGill L.J. 965 at 973.

[184] It has to be noted that the viability of the child and her chances of survival were not an issue in this case. The child was clearly born alive and had actually survived.

[185] *Superintendent of Family and Child Services v. R.D. and S.D.*, [1983] 3 W.W.R. 618, 42 B.C.L.R. 173 [hereinafter: "*Dawson*"]. Hydrocephaly had led to the placement of a ventriculo-peritoneal shunt when Stephen Dawson was five-months old. The child had then been placed by the parents in a facility for chronically handicapped children where he was cared for almost ten hours a day. In 1983, a physician diagnosed a blocked shunt but parents refused to authorize remedial surgery arguing that their child had to be allowed to die in dignity. A child welfare agency promptly filed an application to the Court for an order to carry out the surgery.

contrary, focusing on the protection of human life, the Court stated that a congenitally incompetent person does not lose the rights to health care normally enjoyed by other persons simply in virtue of his or her incompetence. The Court concluded that Stephen had a right to receive the appropriate medical and surgical care "which will assure to him the continuation of his life, such as it is."[186]

In *Couture-Jacquet v. Montreal Children's Hospital*,[187] the legal personhood of a three years and nine months of age child was clearly not at stake.[188] In this case, both the court mentioned the inviolability of the human *person* and focused on the best interests of the child and the medical prognosis.

In *New Brunswick (Minister of Health and Community Services) v. B.(R.) and S.(B.)*,[189] the Family Division of the Court of Queen's Bench in New Brunswick emphasised the right to life of Cara, a very disabled ten-year-old child. Judge McLellan made direct reference to the *Canadian Charter*, which provides that everyone has a right to life, a right not to be subjected to any cruel and unusual treatment and a right to the equal protection of the law without discrimination. The Court concluded that life, "however low its quality",[190] was Cara's right. In this respect, Cara's personhood was clearly not challenged.

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[186] *Ibid.* at 183.
[187] *Couture-Jacquet v. Montreal Children's Hospital* (1986), [1986] R.J.Q. 1221.
[188] The child was suffering from a rare form of cancer and her mother and grandmother refused to consent to a new series of chemotherapy.
[189] *New Brunswick (Minister of Health and Community Services) v. B.(R.) and S.(B.)* (1990), 106 N.B.R. (2d) 206, 265 A.P.R. 206 (Q.B.) [hereinafter: *"Cara B."*].
[190] *Ibid.* at 211, par. [14].

In 1990, in Alberta, First Nations parents refused to consent to a liver transplant on behalf of their 10-month-old son.[191] Considering that the benefits of a transplant were outweighing the harms and that the child could survive with a reasonably good quality of life, the paediatric gastroenterologist called the Department of Social Services which considered that the child was in need of protection and petitioned the Provincial Court of Saskatchewan for temporary custody for the purpose of consenting to the transplant. The judge refused the application on the grounds that qualified medical practitioners disagreed about the merits of a liver transplantation over supportive care. Thus, the court stated that Social Services had failed to prove that the child was in need of protection. In essence, it was the lack of medical consensus or standard of care in favour of the transplant that persuaded the judge to deny the petition, and clearly not considerations related to the personhood of the infant.

Such an overview would not be complete without looking at criminal law. In 1982, in its report on euthanasia, assisted-suicide and cessation of treatment, the Law Reform Commission of Canada considered the legal problems raised by the medical treatment (and non-treatment) of very defective newborns at criminal law.[192] By doing so, the

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[191] *Saskatchewan (Minister of Social Services) v. P.(F.)* (1990), 69 D.L.R. (4th) 134 (Sask. Prov. Ct.). The child had been diagnosed as suffering from biliary atresia.

[192] Law Reform Commission of Canada, *Euthanasia, aiding suicide and cessation of treatment*, Working Paper 28 (Ottawa: Minister of Supply and Services Canada, 1982). It is worth noting that Part II of the Commission's report gives a clear review of the criminal provisions dealing with the life and the physical security of individuals, especially in the context of medical care: *ibid.* at 15-22. In this respect, the Commission concludes that cessation or non-initiation of treatment "may come under a relatively complex set of provisions of the *Criminal Code*, ranging from assault to homicide and including the failure to provide the necessaries of life, failure to use reasonable knowledge, skill and care, and aiding suicide": *ibid.* at 19-20. In this respect, there has been no change in the current situation and the case of radically defective neonates is amply covered by these sections.

Commission expressly stated that "it would be unthinkable to base reform on the recognition of two categories of beings: those recognised as human persons and those not so recognised".[193] According to the Commission:

> To give one concrete example, to deny an anencephalic newborn the status of human person could be justified denying him the protection of the law as well, and thus provide grounds for arguments that killing him directly constitutes neither murder nor criminal negligence. ... The Commission asserts that the law should continue to be based on the fundamental rule now recognised by our criminal law: everyone born of human parents is equally human. In terms of the exercise of subjective rights, we consider that we must continue to respect at least the basic rule of the *Criminal Code* to the effect that a human being is one who has completely proceeded, in a living state, from the body of his or her mother, and must firmly disagree that any such distinction as that between person and non-person should be applied to living humans. Every human person, whatever his degree of handicap, is entitled to the protection of the law. This is particularly important within the context of medical treatment.[194]

The Commission clearly stated that any decision to terminate or not to initiate treatment could not be based on the presence or lack of personhood of a very defective neonate. Such decisions must only be made in accordance with "sound medical practices", namely the relevant standards of care pursuant the current medical knowledge, and must respect the best interests of the neonate.[195] Thus, the child who at birth suffers from defects so severe that, given the current state of medical science, it is certain that he will no survive more than hours or a few days is already engaged in a dying process. Consequently, the physician's duty "is certainly not to abandon the child, anymore than he would abandon an adult patient, but to provide appropriate palliative care and to avoid useless therapeutic measures".[196]

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[193] Law Reform Commission of Canada, *supra* note 192 at 33.
[194] *Ibid.* at 34.
[195] *Ibid.* at 56, 66.
[196] *Ibid.* at 12-3.

It must be noted that the same statement is true in medical malpractice cases involving infants: in such cases, standards of care and "appropriate" care have always been the main concerns and no decision has ever challenged the legal personhood of a very defective neonate in order to negate the responsibilities and duties owed by physicians.

Finally, a few cases pertaining to infanticide[197] and mercy killing in Canada have nevertheless fed the "criminal" debate and may be quite relevant to fully assess the legal personhood of neonates. Canadian law has always treated the murder of an infant by the mother on a different footing than other murders.[198] C. Strange found that in Canada, women who had killed their own baby have systematically been treated leniently by criminal courts.[199] She ads, by commenting the *Latimer* case,[200] that like mercy killing today, infanticide has been widely considered to be a form of murder that did not call for the full severity of law.[201]

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[197] A distinction must be made: infanticide in a strict legal sense is the killing of a newly-born child by his or her mother "if at a time of the act or omission she is not fully recovered from the effects of giving birth to the child and by reason thereof or of the effect of lactation consequent on the birth of the child her mind is then disturbed": see *Criminal Code*, R.S.C. 1985, c. C-46, s. 238(1). In a common sense, infanticide may also designate any killing of a newly-born infant.

[198] C. Strange, "Mercy for Murderers? A Historical Perspective on the Royal Prerogative of Mercy" (2001) 64 Sask. L. Rev. 559.

[199] *Ibid.*

[200] Robert Latimer was twice convicted of second-degree murder by juries in Saskatchewan for the murder of his daughter Tracy. Tracy was born with cerebral palsy and had multiple physical and developmental disabilities. Quadriplegic and suffering from daily multiple seizures, Tracy was in constant pain. Tracy was asphyxiated at twelve-years-old when her father put her in his car and inserted a hose from the truck's exhaust pipe into the cab. Robert Latimer claimed to have acted in his daughter's best interests and asked for an exemption to the existing penalties for murder. The Saskatchewan Court of Appeal held that Latimer must be sentenced to the mandatory minimum sentence. The Supreme Court upheld this decision, stating that the mandatory minimum sentence was not a form of cruel and unusual punishment, despite the circumstances: *R. v. Latimer* (2001), 193 D.L.R. (4th) 577, 150 C.C.C. (3d) 129 (S.C.C.).

[201] C. Strange, *supra* note 198 at 562.

Could that mean that neonates are not considered as full legal persons in criminal law?[202] I will not pretend to be able to answer this question. However, one has to keep in mind that in the cases of infanticide and mercy killing, courts' leniency may be legitimated by considerations related to the individual situation of the authors of these crimes, such as their social status, their mental and medical condition,[203] and their motives. I submit that, as such, these considerations do not compromise the full recognition of the legal personhood of neonates and infants at criminal law. Moreover, we may note that Robert Latimer, who was convicted of second-degree murder, did not benefit from any particular leniency.[204]

In view of the aforementioned cases and the above comments, it appears that Canadian courts do not and will not likely challenge in the future the legal status of very defective neonates either by considering their medical condition and their viability or

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[202] In this respect, it has been argued that an act of intentional killing could not be condoned by the law when the victim possesses a full measure of legal personhood: M.L. Gross, "Abortion and Neonaticide", *supra* note 24 at 226. According to Pinker, even in a current time where infanticide is strictly prohibited, "the leniency [of the courts] shown to neonaticidal mothers forces us to think the unthinkable and ask if we, like many societies and like the mothers themselves, are not completely sure whether a neonate is a full person.": S. Pinker, "Why They Kill Their Newborns" (November 2, 1997) New York Times: http://www.rightgrrl.com/carolyn/pinker.html (accessed February 2003).

[203] In the *Criminal* Code, infanticide involves that the mother has "not fully recovered from the effects of giving birth": see *supra* note 197. This clearly means that medical reasons may justify a different treatment of infanticide than other murders.

[204] A lot has been said and written about this case and some commentators are calling for more leniency and a revision of the sentencing regime for the mercy killers. See I. Grant, "Rethinking the Sentencing Regime for Murder" (2001) 39 Osgoode Hall L.J. 655; M. Jenkins, "Moral Judgement and the Case of Robert Latimer" (2001) 64 Sask. L. Rev. 545; C. Strange, *supra* note 198; R. Johnson, "Confronting the Bogeyman: Latimer, and Other Fearful Tales of Murderous Fathers and Monstrous Children" (2001) 64 Sask. L. Rev. 591. See also the comments on the mercy killing case of Candace Taschuk in Alberta in 1982: S. McCarty, "Confronting Mercy Killing", (June 20, 1983) Report Canada's Independent Newsmagazine: http://report.ca/classics/06201983/p37i830620f.html (accessed June 2003) and E.W. Keyserlingk, "Non-Treatment in the Best Interests of the Child: A Case Commentary of *Couture-Jacquet v. Montreal Children's Hospital*" (1987) 32 McGill L.J. 413 [hereinafter: E.W. Keyserlingk, "Non-Treatment in the Best Interests of the Child"] at 416-7.

by using new criteria imported from the moral personhood theories as exceptionally occurred in *Re Enfant Maude Goyette*.[205] Thus, at law, the decision to treat or not to treat very sick infants does not depend on considerations related to their legal personhood, but mainly on an analysis of their best interests and of the current standards of care.

2. United States

In contrast with Canada, the United States provides us with more explicit references to the legal personhood of very defective neonates. As mentioned above, in this country, the foetus itself has gained a significant and increasing measure of personhood. Therefore, the legal status of neonates, even very defective, seems to be clearly settled.

In the context of treatment and non-treatment decisions, the United States has more judicial and statutory frameworks for neonatal decision-making than most other countries.[206] In this respect, the so-called *Baby Doe* case, which drew public and government attention in 1982, created a significant background that does not exist in Canada. Baby Doe was born in Indiana with a Trisomy 21 (Down's syndrome) and was "allowed" to die (by starvation) after his parents, on the basis of future quality of life considerations, refused to permit the surgery that was necessary to repair his esophagus so that he could be fed. The parents' right to decide what was best for their

[205] *In Re Enfant Maude Goyette*, *supra* note 172.
[206] K.K. Kovach, "Neonatology Life and Death Decisions: Can Mediation Help?" (2000) 28 Cap. U.L. Rev. 251 at 260.

child was upheld by the Indiana Supreme Court. In response to public outcry,[207] the federal government enacted the "Baby Doe rules", which went through extended negotiations and court challenges.[208] In 1984, the *Federal Child Abuse Statute* was amended with guidelines providing that federal funding could be withheld if improper recording for medical neglect of newborns is found.[209] These amendments defined "withholding of medically indicated treatment" as the "failure to respond to the infant's life-threatening condition by providing treatment (including appropriate nutrition, hydration, and medication) which in the treating physician's reasonable medical judgement, will most likely be effective in ameliorating or correcting all such conditions".[210]

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[207] Disability rights and pro-life advocates, supporting an absolute right to life of any neonate, regardless of any quality of life considerations or medical condition were particularly active in this outcry. See J.L. Rosato, "Using Bioethics Discourse to Determine When Parents Should Make Health Care Decisions for Their Children: Is Deference Justified?" (2000) Temple L.R. 1 at 21.

[208] Walters states that the Reagan administration's response to the Baby Doe case "was the most concerted effort by any government in recent times to prevent the application to newborn infants of 'a social ethic where some human lives are valued and some others are not'": S.R. Walters, "Life-Sustaining Medical Decisions Involving Children: Father Knows Best" (1998) T.M. Colley L. Rev. 115 at 133. For more discussion of the Baby Doe regulations and an historical perspective, see also: L.C. Fentiman, "Health Care Acess for Children With Disabilities" (1999) Pace L. Rev. 245; S.K. Kehoe, "Giving The Disabled and Terminally Ill A Voice: Mandating Mediation For All Physician-Assisted Suicide, Withdrawal of Life Support, or Life-Sustaining Treatment Request" (1999) 20 Hamline J. Pub. L. & Pol'y 373 at 386-7; S. Obernberger, "When Love and Abuse Are Not Mutually Exclusive: The Need for Government Intervention" (1997) 12 Issues L. & Med. 355; P.G. Peters Jr., "When Physicians Balk At Futile Care: Implications of the Disability Rights Laws" (1997) Nw. U.L. Rev. 798.

[209] *Child Abuse Prevention and Treatment Act (CAPTA)*, 42 U.S.C §§ 5101-05 (1984).

[210] Nevertheless, the law sets up three exceptions whereby withholding of treatment is deemed proper (1) when the child is in a persistent vegetative state, (2) when the treatment would serve only to prolong the dying process or not fully correct the life-threatening conditions, or (3) where the treatment would be "virtually futile" and "inhumane". For references and analysis of theses exceptions, see S. Obernberger, *supra* note 208.

These provisions do not make special note of the dilemmas of care for very defective neonates and they have been strongly criticised.[211]

Moreover, there is a striking lack of uniformity in the enforcement provisions of the *Federal Child Abuse Statute* through the United States. Obernberger notes that "the potential for the statute to be interpreted fifty different ways and consequently enforced with the same degree of variance creates concerns as to whether children across the country will receive equal protection".[212] Thus, with the approach toward the legal status of the foetus,[213] significant discrepancies exist between the states.[214] Consequently, the American legal background in this context appears to be a complex and tangled web of various regulations and courts decisions. Decisions are determined

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[211] In particular, what may constitute a "virtually futile" and "inhumane" treatment (see supra note 210) is vague and ambiguous: *ibid.* at 375-7. It has also been stressed that the language of the amendments does not take into consideration the fact that a medical treatment in itself could be abusive in certain circumstances and, where it is found to be so, should be stopped in order to fully respect the best interests of the infant: *ibid.* at 377-8. Newman notes that the amendments to the *CAPTA* are strongly influenced by the right-to-life philosophy and that they set a norm for aggressive, even relentless treatment, with little regard for the suffering and grave burdens such aggressive care may generate: S.A. Newman, "Baby Doe, Congress and the States: Challenging the Federal Treatment Standard for Impaired Infants" (1989) 15 Am. J.L. & Med. 1 at 2. However, it must be stressed that, according to the AAP, the amendments have been misinterpreted by many neonatologists, who believe that they are legally constrained to provide aggressive treatment even when their medical judgements and the views of the parents concur that withholding treatment is preferable. In this respect, the AAP asserts that the *Child Abuse Amendments* may actually permit more physician discretion than some realize: AAP, "Ethics and the Care of Critically Ill Infants and Children", *supra* note 72. Similarly, Mahowald notes that "[u]nfortunately, some [physicians] erroneously believe they are legally obliged to treat disabled infants more aggressively than others.": M.B. Mahowald, *supra* note 164 at 338.

[212] S. Obernberger, *supra* note 208 at 379.

[213] See *supra*, Part III, Section B, 2.

[214] Moreover, beside the aforementioned *Child Abuse* amendments and their various state enforcement provisions, the law affecting very defective neonates is also governed by other different federal laws. As noted by Peters, a possibility of discrimination arises whenever a patient's disability plays a role in the physician's determination that life-sustaining treatment would be inappropriate. In this respect, two federal statutes protect disabled individuals from improper discrimination: the *Rehabilitation Act* of 1973 (29 USCS § 701) and the *American with Disabilities Act* of 1991 (ADA, 42 USCS §§ 12101). For discussion of these statutes and their implications, see P.G. Peters Jr., *supra* note 208. Moreover, as discussed below in the *Baby K.* case, the *Emergency Medical Treatment and Active Labor Act* has also a significant impact in the context of non-treatment decisions (see *infra,* Section 2.1).

by different standards, depending on which law governs the issue. Thus, no common standard exists to decide cases in relation to neonatal treatment.[215]

Despite this, I submit that a few statements and revealing examples clearly illustrate that although disparities exist, there is a strong recognition of the legal personhood of the most defective neonates in the United States. Moreover, the following examples demonstrate that in some cases the full recognition of the legal personhood of the most defective neonates had significant consequences on the scope of the duty to treat them.

2.1. The case of anencephalic infants

According to Hughes, United States courts have repeatedly affirmed that the status of being "alive" carries with it a set of legal protections that have nothing to do with the relative capacities or worth of the individual.[216] Discussing the case of anencephalic infants, Hughes argues that the statement that the law recognizes birth as the threshold for full personhood has never been challenged. Thus, "clearly, the live-born anencephalic infant falls within this pronouncement" and are full legal persons.[217] Such a view was clearly affirmed by the courts in Virginia and Florida with significant consequences.

[215] K.K. Kovach, *supra* note 206 at 260.
[216] M.A. Hughes, *supra* note 144 at 312-3.
[217] *Ibid.* at 313.

The first case involved a mother who insisted her anencephalic daughter ("*Baby K.*") to be provided with mechanical breathing assistance, while the attending physicians maintained that such care was clearly inappropriate.[218] However, the infant was brought a few times from the nursing home to the emergency care unit with respiratory distress and the physicians reluctantly complied. As the baby continued to periodically experience such ventilatory crises, her physicians and the hospital went to court seeking a ruling that further aggressive support was not required. The trial judge ruled that the treatment must be continued and a divided Fourth Circuit panel affirmed, basing its decision on the *Emergency Medical Treatment and Active Labour Act* (*EMTALA*).[219]

Thus, the strict application of the law mandated the hospital to treat or, at least, to provide stabilizing treatment to any infant, however defective or viable. The Court of Appeal stressed that the *EMTALA* required hospitals and physicians to provide stabilizing care to any *individual* presenting an emergency medical condition:

> *EMTALA* does not carve out an exception for anencephalic infants in respiratory distress any more than it carves out an exception for comatose patients, those with lung cancer, or those with muscular dystrophy – all of whom may repeatedly seek emergency stabilizing treatment for respiratory distress and also possess an underlying condition that severely affects their quality of life and ultimately may result in their death.[220]

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[218] *In The Matter of Baby K.*, 16 F.3d 590; 1994 U.S. App.

[219] The *Emergency Medical Treatment and Active Labour Act* (*EMTALA*), 42 U.S.C.A. § 1395dd (West 1992) requires all hospitals that provide emergency services to stabilize the condition of patients in need of medical attention. For a presentation of the scope and content of the EMTALA, see for example: K.C. Stanger, "Private Lawsuits Under EMTALA" (2000) 12(5) Health Law 27.

[220] *In The Matter of Baby K.*, *supra* note 218 at 598.

The Court added that it was beyond the limits of its judicial function to address the moral or ethical propriety of providing emergency stabilizing treatment to an anencephalic infant and suggested that physicians who did not like this application of *EMTALA* should ask Congress to change the law.[221]

This decision has been strongly criticized[222] and appears to demonstrate that physicians may have diminishing power to define the boundaries of acceptable care. It is striking to note that the full recognition of the personhood of anencephalic infants and a literal interpretation of the *EMTALA* may lead to the creation of an absolute duty to provide the most defective infants with aggressive treatment in emergency units when so required by the parents, despite the current standards of care and an infants' medical condition or chances of survival.

However, it must be stressed that the significance of the *Baby K.* case appears to be quite limited. One must agree with Fentiman who states that the *Baby K.* decision:

> ...should not be considered a ringing endorsement of parental rights to insist on treatment of handicapped children. Rather, it reflects the limited, patchwork nature of federal regulation of medical treatment decisions, and the isolated and sometimes arbitrary impact of federal laws on physician autonomy in making treatment decisions.[223]

Moreover, this decision has not been followed by other jurisdictions and thus, it would only impose such a duty to treat in the hospitals located in the Florida Fourth Circuit,

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[221] *Ibid.*
[222] See S.M. Whitney, "An Iconoclastic View of Medical Ethics" (2000) 88 Geo. L.J 713, commenting G.J. Annas, *Some Choice: Law, Medicine, and the Market* (New York: Oxford University Press, 1988).
[223] L.C. Fentiman, *supra* note 208 at 261.

because "it is entirely possible that another circuit might reach the opposite conclusion in the same circumstances."[224]

The second case, *In Re T.A.C.P.,*[225] involved a neonate, "*Baby Theresa*", who was born with anencephaly in 1992 in a Florida hospital. The hospital refused the parents' request to declare their child dead so that her organs could be harvested and donated to other children. The Florida Supreme Court noted that Baby Theresa was "alive" "because she was separated from the womb, and was capable of breathing and maintaining a heartbeat independently of her mother's body for some duration of time thereafter".[226]

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[224] S.N. Whitney, *supra* note 222 at 717. In this respect, we may note that the *Baby K.* case is often contrasted with the Michigan "Baby Terry" case (*In re Achtabowski*, 450 Mich. 959; 1995 Mich.) which involved an infant born at 23 weeks of gestation with various and severe ailments (but not anencephaly). The Department of Social Services petitioned a Michigan Circuit Court for a ruling that Baby Terry's parents were guilty of child neglect because they were refusing to discontinue life-sustaining treatment despite the strong recommendations of the attending physicians. In that case, the court simply decided that the parents were incompetent to make medical decisions on behalf of their child. Clearly, it appears difficult to reconcile the Baby K. and Baby Terry cases in a consistent manner. Finally, we may stress that in 1996, the United States Court of Appeals of the Fourth Circuit in Virginia held that *EMTALA* regulates the hospital's care of the patient only in the immediate aftermath of the act of admitting her for emergency treatment: thus, it could not be interpreted to regulate long-term care medical treatment decisions outside this narrow context (see *Bryan v. Rectors and Visitors of the University of Virginia*, 1996 95F.3d 349; 1996 U.S. App.). And in 2002, the Michigan Court of Appeals rejected the claim that an order to withdraw a very defective neonate's life support violated her right to have her emergency medical condition stabilized under the *EMTALA*: the Court found that *EMTALA* does not abrogate the individual's right to consent to medical treatment, and does not affect the authority of the courts to provide procedures for substituted consent in a proper case: *In the Matter of AMB,* 248 Mich.App. 144, 640 N.W.2d 262; 2001 Mich. App.

[225] *In re T.A.C.P., supra* note 145.

[226] *Ibid.* at 593. Similarly, Friedman states that anencephalic infants are capable of spontaneous respiration. Thus, upon birth they qualify as "human beings" under the relevant homicide statutes: J.A. Friedman, *supra* note 53 at 925.

Further, the court held that the current definition of death[227] should not be changed simply to allow more organs donations. The court mainly rested its decision on the applicable Florida statutes and the common law definition of death, but also explored whether a public necessity would justify making an exception for Baby Theresa. In this respect, the court stated that there was no apparent consensus among medical, ethical, or legal authorities on the issue and refused to comment upon the theories that are denying the personhood of anencephalic infants:

> We express no opinion today about who is right and who is wrong on these issues – if any 'right' or 'wrong' can be found here. The salient point is that non consensus exists as to: (a) the utility of organ transplants of the type at issue here; (b) the ethical issues involved; or (c) the legal constitutional problems implicated.[228]

Weighing this lack of consensus against the good that could result from such organ donations, the court concluded:

> Accordingly, we find no basis to expand the common law to equate anencephaly with death. We acknowledge the possibility that some infants' lives might be saved by using organs from anencephalics who do not meet the traditional definition of "death" we reaffirm today. But weighed against this is the utter lack of consensus, and the questions about the overall utility of such organ donations. The scales clearly tip in favour of not extending the common law in this instance.[229]

In summary, by stating that anencephalic infants were protected by the traditional legal definition of death, the court clearly refused to consider these infants as non-persons whose rights would not be protected by the law.

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[227] The common legal definition of death implies a whole brain death, that is the complete and irreversible absence of any brain function. Despite the lack of cerebral cortex, anencephalic infants keep a functioning brain stem for some duration of time after birth.
[228] *In re T.A.C.P.*, *supra* note 145 at 595.
[229] *Ibid.* at 595.

In both cases, live-birth was the only significant criterion of legal personhood admitted by the courts. Viability was not even discussed, implying that legal personhood of defective neonates may be ascertained without reference to such a criterion.[230] Moreover, the courts expressly refused to take position on the moral theories that are denying the personhood of anencephalic infants. By doing so, the courts clearly indicated that they intend to maintain a clear divide between moral theories in relation to the concept of "person" and the legal conception of this notion.

2.2 Live births from late abortions

The case of abortions resulting in live-birth is also quite revealing. It provides important guidance to assess the legal status of very defective neonates whose viability and even live-birth may be challenged at birth. Although legally restricted in many states in America, late-term abortions still occur in a significant measure.[231] Clearly, life-saving technologies are also available for premature infants whose delivery is not spontaneous but results from a failed late-term abortion. Such cases are catastrophic, particularly when a live-birth occurs after a woman psychologically abandoned the prospect of birthing a handicapped child and elected a "therapeutic" abortion. What

[230] However, we may note that pursuant the common standards of care, anencephalic infants are considered as non-viable. See, for example, S. Niermeyer *et al.* and the International Guidelines for Neonatal Resuscitation, *supra* note 159 at 14. Anencephalic infants cases are perfect to demonstrate to what extent "viability" may actually depend on technical means and medical decisions.

[231] See T.W. Strahan, "Psycho-Social Aspects of Late-Term Abortions" (2001) 14(4) Association for Interdisciplinary Research in Values and Social Change: http://www.lifeissues.net/writers/air/air_vol14no4_20001.html (accessed June 2003).

should a physician do if a live infant is born from a late abortion, knowing that rescuing such an infant would obviously defeat the very purpose of an abortion attempt?

In this respect, Rhoden states that determining if the foetus is a person would be particularly relevant in resolving such live-birth issues: "If a foetus is a person with a right to life, then, surely, an infant, including one born of an abortion, is as well."[232] However, Rhoden notes that it is clear that a resolution of the personhood debate is not forthcoming and that, consequently, this debate cannot help us to resolve this live-birth dilemma.[233]

In any case, I submit that if legal personhood depends on the live-birth of the infant, one must admit that there should be no difference between an infant born as a result of abortion or as a result of spontaneous but premature delivery. However, in order to avoid any ambiguity or hesitation on what could constitute "live-birth" or "viability", several states have enacted regulations expressly dealing with such situations. For example, Oklahoma statutes *mandate* the rendering of reasonable medical care during the abortion of a viable child.[234] In Iowa the intentional killing of a "viable foetus aborted alive" is prohibited. That is, if an abortion procedure fails in that it successfully ends the pregnancy but does not successfully terminate the life of the viable foetus, no one can then legally terminate the newborn life.[235] In both cases,

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[232] N.K. Rhoden, *supra* note 155 at 1467.
[233] *Ibid.* at 1467.
[234] The same regulations presume the viability of an unborn child over 24 weeks old. See F. Marouf, *supra* note 132 and *Nealis v. Baird, supra* note 132 at par. [54-59].
[235] J.M. Steffens, *supra* note 131 at 228.

once viable, the foetus/infant has a right to life and thereby to be treated. As a striking consequence, it has been argued that under such regulations, an aborted child might be given greater access to medical care than a naturally born but very premature baby.[236] In other words, a foetus surviving abortion could be given a more significant measure of legal personhood and protection than a spontaneously born infant.

2.3. A strong recognition of legal personhood with significant implications

The above examples clearly speak of a strong recognition of the legal personhood of the most defective neonates in the United States. In the American perspective, the potential implications of this recognition are striking when it comes to assessing the scope of a legal duty to treat very defective neonates.

The aforementioned cases and legislature have gone so far in the recognition of legal personhood and the attached right to life that they have created in certain circumstances a mandatory duty to treat the most defective neonates, and this with no apparent considerations related to their best interests and potential future quality of life and even, sometimes, like in the *Baby K.* case, with no concern for the current medical standards of care. Similarly, it has even been argued that the Supreme Court in *Roe v. Wade*[237] had impliedly "confirmed" that defective newborns are constitutionally

[236] F. Marouf, *supra* note 132. It must be noted that the real goal of these regulations is controversial. In *Nealis v. Baird* (*supra* note 132), the Supreme Court held that the intent of such legislature is to criminalize certain abortions and not to shift the burden of producing evidence on the issues of viability and the appropriate standard of care in wrongful death actions arising from spontaneous delivery: *Nealis v. Baird, supra* note 132 at par. [54-59].
[237] *Roe v. Wade, supra* note 124.

protected *persons* and that, thereby, they could not be allowed to die by treatment decisions.[238] This may be explained by the significant background created by the Baby Doe regulations and the increasing protection afforded to the foetus itself. As a result, in the United States, in order to prevent any form of discrimination, there is a strong idea that life must be preserved at all costs and that the most defective neonates, as actual patients, namely persons, must be treated aggressively unless they are *terminally* ill.[239] Courts remain cautious when it comes to withdrawing or withholding treatment from a neonate.

For instance, in *Re C.A., a Minor,*[240] the Department of Children and Family Services of Illinois filed a petition in the juvenile court for instructions and for authority to consent to the entry of a do-not-resuscitate (DNR) order on a VLBW and premature neonate's medical chart. The Appellate Court of Illinois, mainly relying on medical evidence, granted the petition. But, in its decision, the court made the following comment:

> We certainly do not imply that premature infants should not be resuscitated or otherwise treated, simply because of their prematurity. We live in an age when medical technology can save premature babies, who, a decade or two earlier, would almost certainly have died at birth. C.A., tragically, suffers from a devastating, *deadly* condition that current medical technology cannot cure. We are limiting our opinion to its facts, with the caveat that in cases like this one – where the patient's wishes are not available and the court is involved – someone has to decide.[241]

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[238] T.S. Ellis, "Letting Defective Babies Die: Who Decides?" (1982) 7 Am. J.L. and Med. 393 at 421.

[239] This position was well summarized by the Court of Appeals of Texas in 2000. The Court held that the interest of the State in preserving life is greatest when life can be preserved and weakens as the prognosis dims. According to the Court, parents have no common law right to withhold urgently-needed life-sustaining treatment to their *non-terminally ill* children. To the extent a child's condition has not been certified as terminal, a health care provider is under no duty to follow a parent's instruction to withhold urgently needed life-sustaining treatment from their child. Provided it is subsequently born alive, even an unborn fetus is a patient to whom a doctor treating the mother owes a duty of care. See *HCA, Inc. v. Miller*, 36 S.W.3d 187, 2000 Tex. App.

[240] *In Re C.A., A Minor*, 236 Ill. App. 3d 594; 603 N.E.2d 1171; 1992 Ill. App.

[241] *Ibid.* at 809 (emphasis added).

However, considerations relating to the best interests of defective neonates remain fundamental criteria in treatment or non-treatment decisions and despite restrictive laws, there is evidence that non-treatment decisions may be made on behalf of infants who are not terminally ill or comatose.[242]

For instance, in November 2001, the Michigan Court of Appeals issued a very lengthy decision in the case of *In the Matter of AMB*[243] which involved a premature infant (Allison) affected with severe deformations. In this case, the treating neonatologist believed that life-sustaining support for the infant was not in the child's best interests in consideration of the severe handicaps, suffering and risks faced by the child. However, this neonate was neither terminally ill nor comatose. Despite this, the Court held that the best interests standard was actually the relevant decisional standard and adopted a "clear and convincing evidentiary standard for best interests determinations concerning withdrawing life support".[244] By doing so, the Court did not discuss or challenge the legal personhood of this very defective neonate but stressed that the recognition of this personhood did not equate with an absolute duty to treat them at all costs.

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[242] It has to be noted that despite restrictive laws, there is evidence that parents continue to retain a dominant voice in treatment decisions that are based on the interests of the child and family alike, interests that often include quality of life assessments: M.L. Gross, "Abortion and Neonaticide", *supra* note 24 at 209. According to J. Tyson, under the state laws, best interests standard including quality of life considerations are encouraged. It implies that the restrictive standards described above, in particular the federal Baby Doe regulations, are not always applied in legal cases involving withdrawal of care: See J. Tyson, "Evidence-Based Ethics and the Care of Premature Infants", undated: http://www.futureofchildren.org/bio2857/bio_show.htm?doc_id=80102 (accessed April 2003).

[243] *In the Matter of AMB*, *supra* note 224.

[244] *In the Matter of AMB*, the Court came to the conclusion that such an evidence had not been brought. Thus, Allison's life support should not have been withdrawn.

E. The global picture of legal personhood: coping with ambiguity

There is no doubt that the traditional "born alive and viable rule" has suffered great hardships, especially in the United States where the foetus has been gaining a significant measure of legal personhood. While Canada has not (yet) fallen into the trap of recognizing the legal personhood of a foetus before its birth, it nevertheless still must cope with the consequences of medical progress and the versatile definitions given to the concepts of live-birth and viability. The impact of such concepts on the legal status of very defective neonates has not been assessed. However, at birth, a neonate could theoretically remain a non-person if its vital signs are considered as insufficient, if medical care is not available or not provided for any other reason. This is more striking yet if we admit that viability could still be a necessary pre-condition of legal personhood. Such a concept will always be somewhat arbitrary; its definition will always be contextualised by technological progress and dependent upon disparate practices.

However, after birth, courts have not openly challenged and will not likely challenge the legal personhood of a very defective neonate under a restrictive interpretation of the "born alive and/or viable rule". While this rule has been manipulated and qualified in relation to the legal personhood of foetuses, there has been no similar approach in relation to neonates. Thus, in contrast with the foetuses whose legal status may vary among different bodies of law under different standards, it appears that for very defective neonates, live-birth seems to remain a sufficient condition for their legal personhood.

Similarly, as shown above, North-American courts have never seriously considered ethical theories that would negate the personhood of those who lack so-called essential attributes or intrinsic properties such as self-awareness or the capacity for thought. As a consequence, a legal view that could openly deny the personhood of very defective neonates on such grounds is not likely to be adopted. Accordingly, there seems to be very little disagreement today over the legal personhood a very defective neonate enjoys.[245]

Yet, and this is, perhaps, the most confusing aspect of legal personhood, each nation has defined *the scope and the consequences* of such personhood differently, due to different religious, cultural, historical and political backgrounds.[246] In other words, the debate about the beginning of personhood is just "the tip of the iceberg". In practice, the main issue remains to determine what it means to treat a person as a "person". In the context of the cessation or non-initiation of medical care provided to very defective neonates, this raises the difficult question of determining how and to what extent such neonates should be treated as full persons. In this respect, Canada and the United States adopted their own approaches and standards and have emphasised specific values that were strongly influenced by political and historical backgrounds.

However, it appears that most courts, policies, guidelines and commentators have attempted to answer this question by focusing on the "best interests" of the neonates and the duty to provide them with the "appropriate" medical care. Nevertheless, in this

[245] M.L. Gross, "Abortion and Neonaticide", *supra* note 24 at 216.
[246] *Ibid.* at 203.

context, I contend that it is wrong to believe that the aforementioned ethical theories[247] that negate the moral personhood of very defective neonates are anecdotal and have no legal or practical significance. Certainly, as mentioned above, courts have refused to import the criteria of "personhood" proposed in these theories into the *definition* of the beginning of legal personhood. However, it is less clear to what extent such criteria may actually influence *the scope and the consequences* of legal personhood and the duty to treat the most defective neonates.

As developed below, the concept of moral personhood and the criteria that are attached to it are commonly used as a guideline to make medical decisions in the best interests of very defective neonates. Without caution and full awareness of this phenomenon, legal personhood could well become an illusory fiction.

IV. THE POTENTIAL IMPACT OF MORAL PERSONHOOD ON THE "BEST INTERESTS" ANALYSIS

A. The duty to treat neonates in their best interests

What is it to treat a very defective neonate as a full moral and legal person? In Canada and the United States, ethics and law have mostly focused on the extent of the right of parents to consent to or refuse medical treatment on behalf of their children. The authority of parents as proxy decision-makers is well entrenched in North-American

[247] See *supra* Part II, Section B, 1.

law.[248] However, this parental authority is by no means absolute. As full legal persons, neonates undeniably benefit from the rights to life and to the security of their persons protected by the *Canadian Charter*.[249] A denial to a very defective neonate of equal protection and equal benefit of the law would constitute discrimination on the basis of mental or physical disability, which is prohibited by section 15 of the *Canadian Charter*.[250] As a consequence, courts may intervene when a parental refusal of health care seriously compromises the infant's rights.[251] Accordingly, the common legal benchmark for parents to follow is the "best interests" of the infant.[252] Similarly, a physician's duty is to act in the "best interests" of an infant and to provide "appropriate" care in all circumstances.[253]

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[248] For discussion of parental authority in Canada, see, for example, P.S. Florencio, "Genetics, Parenting, and Children's Rights in the Twenty-First Century" (2000) 45 McGill L.J. 527 at 545, and *B.(R.) v. Children's Aid Society of Metropolitan Toronto*, [1995] 1 S.C.R. 315. The parents' right to make decisions regarding their child's welfare is also paramount in the United States: see, for example, S. Obernberger, *supra* note 208 at 363-5.

[249] See *B.(R.) v. Children's Aid Society of Metropolitan Toronto*, *supra* note 248. This case involves a neonate, Sheena B., who was born four weeks prematurely in June 1983 and was treated with parental consent for a number of ailments. In July, her haemoglobin level had dropped to such an extent that the attending physicians thought she might require a blood transfusion to treat a potentially life-threatening condition. Her Jehovah's Witness parents refused to consent to the transfusion. The Supreme Court of Canada stated that infants could not be considered as objects of property. Infants "undeniably" benefit from the *Canadian Charter*, "most notably in its protection of their rights to life and to the security of their *person*": *ibid.* at 318 (emphasis added). Consequently, the right of parents to make decisions for their infants in fundamental matters such as medical care is not a parental right tantamount to a right of property in children: *ibid.* at 372. In this case, the Court, giving priority to the neonate's best interests, held that a child's right to life could not be so completely subsumed to the parental liberty to make decisions regarding that child.

[250] *E. (Mrs) v. Eve*, [1986] 2. S.C.R. 388 at 436 and Section 15 of the *Canadian Charter*, *supra* note 113.

[251] The courts' *parens patriae* jurisdiction permits them to protect a child in the place of the parents: "Courts have the power to step into the shoes of the parents and make orders in the best interests of the child": see *Winnipeg v. D.F.G.*, *supra* note 97 at par. [49].

[252] See B. Sneiderman *et al.*, *Canadian Medical Law: An Introduction for Physicians, Nurses and other Health Care Professionals* (Toronto: Carswell Thomson Professional Publishing, 1995) at 42-44.

[253] E.I. Picard and G.B. Robertson, *supra* note 18 at 264; B. Sneiderman *et al.*, *supra* note 252 at 149, 496.

Thus, most North-American courts, in adjudicating cases pertaining to treatment/non-treatment decisions made on behalf of children (including neonates), have expressly or implicitly adopted a best interests standard. In contrast with a substituted judgment standard, upon which a surrogate decision-maker should attempt to determine and fulfill the wishes and/or preferences of a previously competent patient, the best interests standard applies when the patient has never been competent.[254] This standard can be defined "as the balance of potential benefit over potential harm or distress resulting from the pursuit of a given line of treatment".[255] Unlike the "subjective" substituted judgement standard, the best interests test is often described as an "objective" approach in that it involves "an appeal to what most reasonable persons would choose in a particular situation of moral choice. "[256]

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[254] In the United States, see for example: *In the Matter of AMB*, *supra* note 224 at 199-201; *In re C.A., a Minor, supra* note 240 at par. [4]; P.A. Gomez, "Promises and Pitfalls: An Analysis of the Shifting Constitutional Interests Involved in the Context of Demanding a Right to Treatment in Health Care" (2000) 64 Alb. L. Rev. 361 at 373-8; J. Stokley, "Withdrawing or Withholding Medical Care from Premature Infants: Who Should Decide, And How?" (1994) 70 N. Dak. L. Rev. 129 at 141-2. In Canada, the British Columbia Supreme Court supported a "substituted judgement" approach in the *Dawson*'s case (*supra* note 185). However, later, in *E. (Mrs) v. Eve* (*supra*, note 250), the Supreme Court of Canada expressly rejected the contention that the best interests of an incompetent person could be appropriately determined by a "substituted judgement standard" and adopted a best interests standard.

[255] CPS, "Treatment decisions for infants and children", *supra* note 68. Similarly, according to the AAP, a best interests standard involves weighing the benefits and burdens of life-sustaining medical treatment: AAP, "Guidelines on Forgoing Life-Sustaining Medical Treatment (RE9406)" (1994) 93(3) Pediatrics 532: http://www.aap.org/policy/00118.html (accessed June 2003). See also T.L. Beauchamp and J.F. Childress, *Principles of biomedical ethics* (ed. 5) (Oxford: University Press, 2001) at 102; A.E. Buchanan and D.W. Brock, *supra* note 31 at 123; K.C. Glass, *supra* note 9 at 39, quoting N. Fost, "Ethical Issues in Death and Dying" in B.P. Fuhrman and J.J. Zimmerman, eds., *Pediatric Critical Care* (ed. 2) (St-Louis, MO: Mosby, 1998); E.W. Keyserlingk, "Non-Treatment in the Best Interests of the Child", *supra* note 204 at 434; J.L. Rosato, *supra* note 207 at 11; R.F. Weir, *supra* note 39 at 198.

[256] R.F. Weir, *supra* note 39 at 198. Accordingly, see N.L. Cantor, "Philosophy and Law: the Real Ethic of Death and Dying" (1996) 94 Mich. L. Rev. 1718 at 1733; E.H.W. Kluge, "After 'Eve': Whither Proxy Decision-Making" in E. Boetzkes and W.J. Waluchow, eds., *Readings in Health Care Ethics* (Ontario: Broadview Press Ltd, 2000) [hereinafter: E.H.W. Kluge, "After Eve"] at 148; D.L. Moore, "Challenging Parental Decisions To Overtreat Children" (1995) Health Matrix 311 at 321-2; J. Stokley, *supra* note 254 at 142. *Contra*: see in particular *E. (Mrs) v. Eve*, in which the Supreme Court of Canada stated that the best interests test is "not an objective test and it is not intended to be": *supra* note 250 at 432.

However, what constitutes the "objective" factors involved in the assessment of the "best interests" of very defective neonates is a question of considerable difficulty. In this field, there are no substantive guiding principles or common factors that could be simply interpreted and applied in every individual case.[257] Moreover, the importance of each factor may vary depending upon such influences as culture or religion.[258]

As stated by Keyserlingk, the judicial determination of what constitutes an infant's best interests "cannot be precisely calculated by the application of mathematical formulae. It is a matter of judgement arrived at by weighing and balancing all the relevant facts and perspectives provided by the parties involved".[259]

In substance, a "best interests" analysis may be influenced by two main distinct approaches that are not necessarily exclusive from each other, namely the "sanctity of life" and "quality of life" approaches. [260]

The "sanctity of life" position, often associated with a religious vitalist perspective, holds that the value of life exceeds all other values. In this view, life is valued *per*

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[257] See for example: J.L. Rosato, *supra*, note 207 at 5; AAP, "Ethics and the Care of Critically Ill Infants and Children", *supra* note 72.
[258] K.K. Kovach, *supra* note 206 at 257.
[259] E.W. Keyserlingk, "Non-Treatment in the Best Interests of the Child", *supra* note 204 at 425-6
[260] There is no space here to develop the many distinctions and nuances that have been elaborated and commented around these approaches. It would also be too long to dissect all of factors which could be or are actually involved in making medical treatment decisions in the best interests of neonates. However, a short presentation of these approaches and a few examples will suffice to elucidate the potential influence of the concept of "moral person" in a "best interests" analysis.

se.[261] Thus, "wherever there is human life, any human life, whether comatose life, foetal life, deformed or suffering life, the sanctity of life principle is the final, conclusive reason against ceasing to preserve it."[262] In this perspective, a duty to treat very defective neonates exists as soon and as long as they show the slightest vital sign. Accordingly, those who assume that life is an absolute intrinsic value[263] may maintain that the prolongation of an infant's life is always in her or his best interests.[264]

However, most supporters of the sanctity of life principle do not go this far.[265] Such an absolute position has rarely been supported by any North-American ethical guidelines, statutes or courts.[266] Despite a persistent and strong assumption in favour of life, courts and guidelines generally agree that there are circumstances in which *it is in the*

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[261] P. Suber, "Against the Sanctity of Life" (1996): www.earlham.edu/~peters/writing/sanctity.htm (accessed April 2003). For more discussion of the vitalist positions and the sanctity of life theories, see for example: K.M. Boozang, "An Intimate Passing: Restoring the Role of Family and Religion in Dying" (1997) 58 U. Pitt. L. Rev. 549 at 567-70; M.A. Crossley, "Of Diagnoses and Discrimination: Discriminatory Nontreatment of Infants With HIV Infection" (1993) 93 Colum. L. Rev. 1581 at 1622-3; L. Gostin, "A Moment in Human Development: Legal Protection, Ethical Standards and Social Policy on the Selective Non-treatment of Handicapped Neonates" (1985) 11 Am. J.L. and Med. 31 at 36-8; E.W. Keyserlingk, *Sanctity of Life or Quality of Life*, *supra* note 20; K.D. Kilback, " To Be Human: Selective Reflections on the Sanctity of Life in Rodriguez" (1994) 2 Health L. J. 39; H. Kuhse, *supra* note 66.

[262] E.W. Keyserlingk, *Sanctity of Life or Quality of Life*, *supra* note 20 at 20.

[263] As mentioned above (*supra* note 260), there are different perceptions of the sanctity of life principle. The vitalist approach is only one of them. According to Keyserlingk, for instance, the sanctity of life principle "does not mean vitalism" but "it insists that human life is always worthy of respect and protection, and that it should always be supported *without adequate justification to the contrary*.": E.W. Keyserlingk, *Sanctity of life or quality of life*, *supra* note 20 at 49 (emphasis added).

[264] Mahowald notes that "[i]n this respect, the prolongation of the live of a very defective infant may *per se* always be in her best interests": M.B. Mahowald, *supra* note 164 at 335.

[265] See K.M. Boozang, *supra* note 261 at 568.

[266] Gostin notes that in the United States, the Child Abuse provisions (see *supra* notes 209-211) essentially adopt a vitalist position by requiring treatment in virtually all cases where the infant has the potential to survive: L. Gostin, *supra* note 261 at 70, 71. However, it must be noted that the federal law sets up three exceptions whereby withholding of treatment is deemed proper: see *supra* note 210. As shown above (*supra* Part III, Section D. 1), such a restrictive law does not exist in Canada. In any case, as stressed by Gostin: "... even those courts with vitalist preconceptions have not foreclosed the possibility that a minor's interests may be best served by non-treatment.": *ibid.* at 58.

infant's best interests, and therefore legally and morally acceptable, to withhold or withdraw treatment. As stated by Obernberger, "overtreatment" is rarely in the best interests of an infant.[267] Thus, it is commonly admitted that that life-sustaining or life prolonging treatment could and even should not be provided when the infant's death is "unavoidable" and/or "imminent" or when the treatment would be "clearly ineffective" or "harmful".[268] It must be stressed, however, that certain courts' decisions, such as the Florida *Baby K.*[269] and New Brunswick *Cara B.*[270] cases, remain ambiguous in this respect. Moreover, what may constitute "imminent" or "unavoidable" death, and "futile", "ineffective" or "harmful" treatment is extremely controversial, especially in neonatology where medical prognosis is often made under conditions of great uncertainty.[271]

In any case, all the more problematical are the truly ambiguous cases in which it is not clear whether the treatment is in the best interests of a very defective neonate *who is not dying* but who is seriously ill and will likely suffer from significant physical or mental damages. In this respect, an approach which does not subscribe to the vitalist

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[267] S. Obernberger, *supra* note 208 at 381.

[268] It appears clearly in a comprehensive overview presented by the Court of Appeal of California in 2003: *In re Christopher I.*, 106 Cal. App. 4th 533, 131 Cal. Rptr. 2d 122; 2003 Cal. App. See also: *Child Abuse Prevention and Treatment Act, supra* notes 209 and 210; AAP, "Ethics and Care of Critically Ill Infants and Children (RE9624)", *supra* note 72. In Canada, see for instance: Law Reform Commission of Canada, *supra* note 192 at 13, 41; CPS, "Treatment decisions for infants and children", *supra* note 68. See also the review of Canadian cases presented by B. Sneidermann *et al.*, *supra* note 252 at 486-501.

[269] See *supra* note 218 and Part III, Section D, 2.1.

[270] In the Canadian case of *Cara B.*, the New Brunswick Family Division of the Court of Queen's Bench clearly supported a vitalist approach by ordering the provision of life-extending treatment for a severely handicapped child regardless of prognosis and quality of life considerations: *supra*, note 189 and Part III, Section D, 1.

[271] Indeed, physicians, parents, ethicists, and courts do not always agree on whether a proposed treatment is "clearly futile" or not. It must be noted that an exhaustive review of the arguments linked to such issues would obviously go beyond the scope of this thesis. See *supra* note 211.

interpretation of the sanctity of life principle has developed. This approach integrates so-called "quality of life" considerations in the assessment of the infant's best interests. As noted by Gostin, "[t]he term 'quality of life' has been introduced into Anglo-American jurisprudence and by commentators to justify the withholding of medically indicated treatment for severely handicapped infants whose life would be so bereft of enjoyment as not to be worth living."[272]

In the United States, despite restrictive laws, most states permit surrogates to take certain quality of life considerations into account when making treatment or non-treatment decisions and the other states do so without admitting it.[273] In Canada, in 1982, the Law Reform Commission of Canada clearly stated that "*something more* than a merely quantitative aspect to human life" should be recognized and that "considerations of quality of life can be legitimate factors in decision making and valid criteria in justifying certain acts which may appear to be threats to life seen from an exclusively quantitative perspective".[274] The Commission added that "[i]n medical law, this has already long been recognized in practice."[275]

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[272] L. Gostin, *supra* note 261 at 40.

[273] P.G. Peters, *supra* note 208 at 832. See also J. Tyson, *supra* note 242 and K.M. Boozang, *supra* note 261 at 579-83. In 1976, the Supreme Court of New Jersey expressly affirmed that quality of life factors are legally acceptable considerations in making decisions to continue or stop life-support: *In re Quinlan*, *supra* note 177, and E.W. Keyserlingk, "Non-Treatment in the Best Interests of the Child", *supra* note 204 at 431. However, this statement is relativized by Magnet and Kluge who claim that the basis of the *Quinlan* case and the decisions that have upheld the right to refuse treatment on behalf of comatose patients is narrow. According to these authors, the American courts do not assume in those cases any broad jurisdiction to adjudicate quality of life. Rather, these cases deal with life in the comatose, non-cognitive, vegetative state. Therefore, the scope of these decisions could be limited to the cases of patients – and these patients only – who have definitely lost their cognitive functions: J.E. Magnet and E.H.W. Kluge, *supra* note 42 at 85-6.

[274] Law Reform Commission of Canada, *supra* note 192 at 38-9 (emphasis added).

[275] *Ibid.* at 39.

Thus, it appears that a best interests analysis should and could both legally and ethically involve *certain* quality of life considerations.[276] Yet, this raises major concerns. In particular, the phrase "quality of life" describes a wide diversity of ethical standards[277] and the content of this concept is rarely specified.[278] Therefore, what meaning must be given to "quality of life"? Without doubt, the concept of a "life worth living" is central to the "quality of life" position.[279] In this respect, I will demonstrate below that any attempt to delineate the contours of a life worth living under a best interests analysis unavoidably involves considerations and criteria that are closely related to the various and controversial moral personhood theories presented in Part II.

B. Quality of life considerations

It would be an impossible task to list all the parameters that have been proposed to describe what may constitute a life worth living or a life with an "acceptable" quality under a best interests analysis. As stressed by Suber, such a list "is unattainable in part

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[276] A.E. Buchanan and D.W. Brock, *supra* note 31 at 123 and T.L. Beauchamp and J.F. Childress, *supra* note 255 at 102. For a short review of legal cases involving quality of life argumentation, see *infra* Section B.

[277] M.A. Crossley notes that "[a]t the end of the spectrum furthest from either sanctity of life approach are those commentators who argue not only that an infant's future quality of life is an ethically valid consideration, but that assessing quality of life should include an utilitarian consideration on how the infant's life will affect other individuals and society, including the burdens that caring for a disabled infant may place on the infant's family.": M.A. Crossley, *supra* note 261 at 1624.

[278] L. Gostin, *supra* note 261 at 41; E.W. Keyserlingk, *Sanctity of Life or Quality of Life*, *supra* note 20 at 51.

[279] A.E. Buchanan and D.W. Brock, *supra* note 31 at 123; L. Gostin, *supra* note 261 at 40, E.W. Keyserlingk, "Non-Treatment in the Best Interests of the Child", *supra* note 204 at 51; P. Suber, *supra* note 261 in Section 2.

because of the disagreement of individual quality of life proponents and the divisions within the societies they reflect. But it is also unattainable because of the diversity of ways in which a life can be mutilated and diminished."[280]

Some commentators mainly require that a life possess some positive features to be worth living such as consciousness (or awareness),[281] self-consciousness (or self-awareness),[282] intelligence (or rationality, sapience),[283] ability to communicate, to recognize and interact with others,[284] capacity to feel pain and emotions (or sentience),[285] autonomy,[286] ability to enjoy life and have pleasure,[287] and potential for achieving personal satisfaction.[288] Other proponents focus on negative features that would preclude a life worth living such as extreme and intractable pain, hopeless deterioration, irreversible incapacity, and even absence of sense perception (such as sight and hearing).[289] Also, both approaches can be combined "to hold that a life is

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[280] P. Suber, *supra* note 261 in Section 2.
[281] L. Gostin, *supra* note 261 at 42, 43; E.H.W. Kluge, "After Eve", *supra* note 256 at 147, 152; H. Kuhse, *supra* note 66 at 213.
[282] A.E. Buchanan and D.W. Brock, *supra* note 31 at 248.
[283] L. Gostin, *supra* note 261 at 42; E.H.W. Kluge, "After Eve", *supra* note 256 at 152; P. Suber, *supra* note 261 in Section 2.2.
[284] Most authors insist on the potential for interaction with others or the potential for present and future human relationships: M.A. Crossley, *supra* note 261 at 1627; L. Gostin, *supra* note 261 at 4; E.W. Keyserlingk, *Sanctity of Life or Quality of Life*, *supra* note 20 at 70; E.H.W. Kluge, "After Eve", *supra* note 256 at 147; N.K. Rhoden, "Treatment Dilemmas for Imperiled Newborns: Why Quality of Life Counts" (1985) 58 S. Cal. L. Rev. 1283 [hereinafter: N.K. Rhoden, "Treatment Dilemmas"] at 1320, 1322. Brock and Buchanan insist on the capacity to be a "social agent" and on the potential for personal relationships such as friendship, love, intimacy, ties of loyalty and caring: A.E. Buchanan and D.W. Brock, *supra* note 31 at 247-9.
[285] A.E. Buchanan and D.W. Brock, *supra* note 31 at 248; L. Gostin, *supra* note 261 at 43; N.K. Rhoden, "Treatment Dilemmas", *supra* note 284 at 1320.
[286] P. Suber, *supra* note 261 in Section 2.2.
[287] A.E. Buchanan and D.W. Brock, *supra* note 31 at 264; L. Gostin, *supra* note 261 at 40; H. Kuhse, *supra* note 66 at 218; N.K. Rhoden, "Treatment Dilemmas", *supra* note 284 at 1320.
[288] L. Gostin, *supra* note 261 at 43.
[289] L. Gostin, *supra* note 261 at 45.

worth living only if certain positive features are present and certain negative features absent."[290]

As mentioned above, North-American courts themselves have referred to quality of life considerations by assessing the best interests of infants and children in the context of medical care. In a recent case, the Court of Appeal of California examined the factors that should be considered in determining whether it is in a child's best interests to withhold or withdraw life-sustaining treatment.[291] By so doing, the court gave a broad review of the American jurisprudence and doctrine on this question.[292] The following factors were notably identified: the degree of physical pain, the preservation and restoration of physical, sensory, emotional and cognitive functioning, the degree of humiliation, dependence and loss of dignity probably resulting from the condition and treatment, and the quality of life, life expectancy and prognosis for recovery without treatment, including the futility of continued treatment.[293]

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[290] P. Suber, *supra* note 261 in Section 2.2.

[291] *In re Christopher I.*, *supra* note 268. This case involves a 3 months old infant, who, as a result of physical abuse by his father, was in a persistent vegetative state, surviving only by the aid of a ventilator. On appeal, the court affirmed the judgement which ordered the removal of life-support.

[292] The court noted that most jurisdictions throughout the United States have employed the same factors in considering questions of withholding or withdrawing life-sustaining medical treatment from incompetent patients: *ibid.* at 551.

[293] The court stressed that such a list of factors is not meant to be exclusive "but it is intended to provide a set of factors to be considered, analysed and weighed." The court added: "Not all of these factors may be applicable in a given case. The court is not limited to consideration of only these factors, and may take other factors into account when appropriate, especially as medical science and technology develop.": *ibid.* at 551-2. The court also referred to cases involving elderly patients such as *In re Conroy* (*In re Conroy*, 98 N.J. 321, 486 A.2d 1209; N.J. 1985) and stressed that the same factors could be employed for infants and children: *ibid.* at 551. In this respect, it is worth noting that *In re Conroy*, the New Jersey Supreme Court expressly held that the assessment of the benefits of life-sustaining medical treatment under a best interests analysis should include the evaluation of the quality of life after such treatment has been applied. In such an evaluation, the New Jersey court took into account the reduction of pain and disability, and the increase of "physical pleasure, emotional enjoyment, and intellectual satisfaction.": *In re Conroy, supra* at 1232-3. For examples in other jurisdictions, see: *In the Matter of AMB, supra* note 224;

In Canada, with the noticeable exceptions of *Cara B.*'s case[294] and, to a certain extent, *Dawson* case,[295] courts have also considered quality of life factors as significant and acceptable considerations in the context of the medical treatment provided to children or infants. However, courts were rarely explicit in how to interpret the concept of "quality of life". In *Re Enfant Maude Goyette*,[296] for example, the court clearly stated that the negative side effects of the treatment had to be weighed against the possibility of eventual improvement in the quality of life of the infant but did not provide a clear picture of the applicable standards and criteria involved by this. Yet, the reference to the *Quinlan* case[297] leads us to think that the court took into consideration the presence (or absence) of *cognitive functions* to assess the quality of life of the child.

Moreover, the court held that when life has become "inhuman", the loss of the dignity of the person, understood as the loss of all significant quality of life, could justify the refusal of a given line of aggressive treatment:

In re Rosenbush, 195 Mich. App. 675; 491 N.W.2d 633; 1992 Mich. App. and the references given by the Court of Appeal of California in *In re Christopher I.*, *supra* note 268. Finally, it may be noted that identical factors have been adopted by the AAP: "Guidelines on Forgoing Life-Sustaining Medical Treatment (RE9406)", *supra* note 255.

[294] *Cara B.*, *supra* notes 189, 270.

[295] In the *Dawson* case (*supra* note 185), the British Columbia Supreme Court considered quality of life considerations involving the capacity for sapient cognitive awareness, the possibility of relatively pain-free and physically comfortable existence, and the potential for meaningful social interaction. However, the court refused to give them significant weight in the given case. The court held that it was not the prerogative of the parents or any court to "look down upon a disadvantaged person and judge the quality of that person's life to be so low as not to be deserving of continuance" (*ibid.* at 184) and that Stephen Dawson had "the right to receive appropriate medical and surgical care of a relatively simple kind which will assure to him the continuation of his life, such as it is" (*ibid.* at 183). However, according to Keyserlingk, such a position can be explained by the particular facts of the case and does not preclude such quality of life considerations under a best interests analysis: E. W. Keyserlingk, "Non-Treatment in the Best Interests of the Child", *supra* note 204 at 433-4.

[296] *Re Enfant Maude Goyette*, *supra* note 172.

[297] See *supra* Part III, Section D, 1 and note 177.

> ...la notion de la "qualité de la vie" se confond avec celle de la "dignité de l'être humain" et la "dignité et la valeur de la personne humaine"[298] ... L'Etat doit préserver la vie humaine, mais si, malgré les soins, la vie devient inhumaine, c'est la dignité de la personne qui doit l'emporter sur l'intérêt de l'Etat.[299]

Another example may be found in *La Commission de Protection des Droits de la Jeunesse v. C.T.*,[300] where the Superior Court of Quebec implicitly referred to quality of life considerations by asking this question:

> Affligée d'un déficit mental probable, cette enfant pourra-t-elle se développer sur *le plan de la communication* avec le monde extérieur de façon raisonnable?[301]

In other cases, courts were even less explicit: they were contented to stress that the negative effects of the treatment on the child must be weighed against the possibility of eventual improvement in the "quality of life" of the infant but gave no clear picture of the content of this latter concept.[302] In this respect, the least explicit case is without doubt *Child and Family Services of Central Manitoba v. R.L. and S.L.H.* [303] The question before the Manitoba Court of Appeal was whether a physician could, over the objection of the parents, enter a DNR (do-not-resuscitate) order on the chart of a 11 months old child who was in a persistent vegetative state (PVS). In substance, without

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[298] *Re Enfant Maude Goyette*, *supra* note 172 at 434.
[299] *Re Enfant Maude Goyette*, *supra* note 172 at 436.
[300] *La Commission de Protection des Droits de la Jeunesse v. C.T*, *supra* note 181.
[301] *Ibid.* at 1681 (emphasis added). The court did not answer this question, but concluded that, in any respect, the parental decision to refuse treatment on behalf of their infant was not unreasonable.
[302] See *Couture-Jacquet v. Montreal Children's Hospital*, *supra* note 187; *Saskatchewan (Minister of Social Services) v. P.(F.)*, *supra*, note 191. For a review and comment of courts' decisions in this respect, see E.W. Keyserlingk, "Non-Treatment in the Best Interests of the Child", *supra* note 204 and B. Sneiderman *et al.*, *supra* note 252 at 487-501.
[303] *Child and Family Services of Central Manitoba v. R.L. and S.L.H.*. (1997) 154 D.L.R. (4th) 409; 123 Man. R.(2d) 135.

addressing the fundamental ethical issues at stake, the court disposed of the question in one ambiguous sentence: "Philosophical arguments apart, it is in no one's interest to artificially maintain the life of a patient who is in an irreversible vegetative state."[304] Yet, such a judgement obviously involves quality of life considerations. As stated by Sneiderman, "[s]urely, the question warrants more than the cursory treatment afforded by the Manitoba court."[305]

In any case, one cannot deny that all the parameters exposed above and proposed by the aforementioned commentators[306] and the courts to describe an acceptable quality of life bear a striking resemblance to the criteria that are used by authors such as Engelhardt, Fletcher, Harris, Singer, and Tooley[307] to negate the moral personhood of very defective neonates and other categories of patients.

We may then wonder if the practical and legal use of quality of life considerations under a best interests analysis might lead us to the same conclusions drawn by these authors. In other words, there is the critical question of whether the moral and legal status of very defective neonates is threatened by a best interests analysis that includes quality of life considerations.

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[304] *Ibid.* at 137.
[305] B. 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 L.J. 205 at 212.
[306] See *supra* notes 278-289.
[307] See *supra* Part II.

C. Moral personhood and best interests of very defective neonates

As demonstrated above, it is erroneous to assume that there is a clear delineation between a best interests analysis that includes quality of life considerations on the one hand, and the moral personhood theories presented in Part II and against which polemic is raging on the other hand.

In this respect, Professor Keyserlingk's position is revealing whereby he opines that the concept of person should precisely be a central quality of life consideration in the context of medical treatment.[308] He claims that a normative definition of person encompassing stable attributes or inherent features for use in decisions to initiate, continue or discontinue treatment is both possible and desirable. Consequently, "[t]he determination of a minimum capacity to experience and relate should always be considered the indispensable and most important quality of life norm" in this context.[309]

As a matter of fact, the opponents of moral personhood theories have argued that the use of the notion of moral personhood in medical decision making was "harmful and dangerous", in particular because it could lead to an unacceptable discrimination towards the weakest members of our society.[310] Yet, there is no major difference in this respect with the critiques that have been expressed against the quality of life

[308] E.W. Keyserlingk, *Sanctity of Life or Quality of Life*, *supra* note 20 at 104-105.
[309] *Ibid.*
[310] *Ibid.* at 81-2 and references, and S. Schwarz, *supra* note 49.

positions. Indeed, the risk of discrimination in the use of quality of life considerations under a best interests standard is also a major concern.

In *Dawson*, for instance, Judge Justice McKenzie implied that quality of life considerations such as sapient cognitive awareness and the potential for meaningful social interaction "would mean regarding the life of a handicapped child as not only less valuable than the life of a normal child, but so much less valuable that it is not worth preserving."[311]

Similarly, as described by Keyserlingk, the opponents of quality of life considerations in medical decision-making generally claim that quality of life considerations "inevitably and fundamentally involve more or less subjective judgements about the relative individual or social worth, value, usefulness or equality of the lives of the persons."[312] As such, like personhood theories, quality of life judgements are especially controversial because they may be assumed to imply that the value of life is reduced when the patient has a severe disability.[313]

However, other commentators have carefully attempted to soothe such concerns by stressing that "properly used", quality of life judgements "do not concern the social worth of individuals, but rather the value of the life for the *person* who must live with

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[311] Judge McKenzie added: "I tremble at contemplating the consequences if the lives of disabled persons are dependent upon such judgements.": see *Dawson*, *supra* note 185 and 295 at 187.
[312] E.W. Keyserlingk, *Sanctity of life or Quality of Life*, *supra* note 20 at 51. To avoid any misunderstanding, it must be stressed that Keyserlinkg is not an opponent of quality of life considerations in a medical context. This quotation constitutes only his description of the most frequent concern voiced by the opponents of such considerations.
[313] P.G. Peters, *supra* note 208 at 862.

it."[314] In this perspective, a best interests analysis including quality of life judgements does focus attention on the interests of the defective neonates and not on the value their lives have for other persons or society.[315]

Thus, according to Weir:

> [B]y focusing on the infant whose life hangs in the balance in nontreatment decisions and by emphasising the best interests of the infant in question rather than concentrating on the desires of parents or the interests of other parties in neonatal cases, the ambiguous aspects of quality of life judgements that compromise the moral status of neonates may be removed.[316]

Similarly, it is by focusing on the "objective" nature of a best interests analysis[317] and by relativising parents' or physicians' personal preferences in treatment decisions that the courts have attempted to evade the risk of discrimination created by value-laden and subjective quality of life judgements. Nevertheless, it has to be noted that according to many commentators, parental preferences and the interests of others and of society in general are also significant factors that can or even must be taken into

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[314] T.L. Beauchamp and J.F. Childress, *supra* note 255 at 103.
[315] *Ibid.* at 103; A.E. Buchanan and D.W. Brock, *supra* note 31 at 123-4. According to P. Suber, "[w]hen quality of life proponents speak of a life not worth living, they usually mean not worth living to the individual, not to the individual's next of kin, emotional and financial dependents, or even society.": P. Suber, *supra* note 261 in Section 2.
[316] R.F. Weir, *supra* note 39 at 171.
[317] See *supra* Part IV, Section A and note 256. As mentioned above, the assessment of the best interests of a defective neonate involves an appeal to what most *reasonable* persons would choose in a particular situation. In this respect, Canadian courts have often stressed that their power to infringe on parental authority to make treatment decisions on behalf of their children or infants was limited in that they had to determine if a parental refusal to provide medical treatment was "reasonable" (or not) under the particular circumstances of the case. See, for instance, *La Commission de Protection des Droits de la Jeunesse v. C.T*, *supra* note 181.

consideration under a best interests analysis. However, such factors cannot be decisive and should never override the interests of the child.[318]

Thus, it appears that despite the striking similarities that exist between the factors involved in moral personhood theories and quality of life criteria, the current approach of a best interests analysis considerably limits the threats to the moral status of very defective neonates. However, parents, physicians, ethicists and courts must be fully aware that there might be a significant gap between theory and reality. A reference to an objective standard that could describe what is an intolerable quality of life does certainly not preclude any ambiguity. I have demonstrated above that there is no such thing as a universal and common definition of what constitutes a "person".[319] Likewise, there is no such thing as a common and objective definition of what constitutes an intolerable life. Unless we achieve a common understanding of this concept, any surrogate decision maker will unavoidably include her or his own subjective perceptions. For instance, how to consider objectively the future and potential capacity of a very defective neonate to relate to others without considering

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[318] See, for example, K.C. Glass, *supra* note 9 at 38. Other authors do not share this opinion. Boozang claim that families should not be restrained by the child's best interests standard and that more deference should be given to their personal opinions and preferences: K.M. Boozang, *supra* note 261. According to S.J. Parsons, a best interests standard applied to life and death considerations regarding infants is invalid, as infants do not have present desires. Thus, he claims that "all that matters" is what parents "rationally desire, after being informed of the facts and the consequences, for that ... infant": J.S. Parson, "Present self-represented futures of value are a reason for the wrongness of killing", (2002) 28 J. Med. Ethics 196 at 196-7. Within the legal sphere, it is worth stressing that *In re Christopher I.*, the Californian Court of Appeal held that "the opinions of the family, the reasons behind those opinions, and the reasons why the family either has no opinion or cannot agree on a course of treatment" were significant factors in determining the best interests of the child: see *In re Christopher I., supra* note 268 at 134-5. Finally, it is worth noting that in *Child and Family Services of Central Manitoba v. R.L. and S.L.H.* (*supra*, note 303), the Manitoba court's pronouncement that it is in "no one's interests" to maintain the life of a PVS patient is extremely ambiguous: we may wonder whose interests are paramount here...

[319] See *supra*, Part II.

our own capacity to relate to her or him and our own perceptions of the potential handicap? Where does a decision to treat or not to treat a very defective neonate cease to be reasonable in this context? Reasonableness is necessarily based on a social consensus.[320] That is, in the words of Rosato:

> If a decision is outside the range of what reasonable people would choose, it is unlikely that the decision would be in a particular patient's best interests, assuming that what serves the welfare of almost all patients is likely to serve the welfare of a particular patient.[321]

In this respect, the risks of discrimination and the threats to the moral status of very defective neonates may result from the social perceptions of what constitutes a "reasonable" decision and, thereby, from the social common understanding of the concept of "person". It has been demonstrated above that as a social perception, personhood is still diminished by disability.[322] Moreover, "normal persons may view a particular handicap with horror, while the handicapped individual, whose choices are life with this defect or death, may strongly prefer life with the handicap."[323] Indeed, studies tend to demonstrate that very defective neonates who have survived beyond infancy with severe handicaps that could have legitimated the cessation of life-sustaining treatment under quality of life considerations self-report excellent or good overall health.[324] We may understand in this respect the potential impact of our own subjective perceptions of disabilities on quality of life considerations and I maintain,

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[320] J.L. Rosato, *supra* note 207 at 54.
[321] *Ibid.* at 44.
[322] G. Landsman, *supra* note 25 at 1947-8.
[323] N.K. Rhoden, *supra* note 155 at 1484.
[324] See for example: E. Feingold *et al.*, "HRLQ and Severity of Brain Ultrasound Findings in a Cohort of Adolescents Who Were Born Preterm" (2002) 31 Journal of Adolescent Health 234, http://www.elsevier.com/locate/jahonline (accessed August 2003); S. Saigal *et al,* "Self-Esteem of Adolescents Who Were Born Prematurely" (2002) 109(3) Pediatrics 429.

as Buchanan and Brock do,[325] that there is an irreducible element of subjectivity in any quality of life consideration.

Thus, depending on the social or personal meanings given to the concept of "person" and the social or personal perceptions of disabilities, quality of life considerations like personhood theories are challenging the moral status of neonates.

Yet, my contention is certainly not to claim that a best interests analysis including quality of life considerations and theories of moral personhood are identical or bear the same implications. Fundamental differences still remain. In particular, a best interests analysis rests on the premise that a neonate is a "person", who has interests that must be protected, whatever her or his medical condition. Conversely, extreme personhood theories tend to claim that "non-persons" have no interests or very limited interests that should be morally and legally protected.[326] Consequently, the authors of personhood theories are prone to admit that the active killing of a non-person, who has no desires or preferences and no interest in a continued life is morally acceptable.[327] Such extreme viewpoints go far beyond the potential outcomes resulting from the use of quality of life factors under a best interests standard. Nevertheless, it cannot be denied that in Europe, the accuracy of this latter statement has become uncertain in the

[325] A.E. Buchanan and D.W. Brock, *supra* note 31 at 252.
[326] See *supra* Part II, Section 4 and the non-interests theories linked to anencephalic infants.
[327] For instance, Kuhse claims that "the notion of the person as employed by Tooley, reflects no arbitrary species-based boundary, but characteristics of obvious relevance to the taking of life and the infliction of pain and suffering.": H. Kuhse, *supra* note 66 at 215. She concludes that "a quality of life ethics entail that the direct wrongness of killing lies not in taking life, but rather in overriding in a most profound way the interests, desires, and preferences of a person who does not want to die.": *ibid.* at 216.

case of very defective neonates. In this respect, the French position is certainly the most striking example of the potential outcomes resulting from an ambiguous interpretation of the moral personhood of neonates and an analogy that is too close between a best interests standards including quality of life considerations and moral personhood theories.[328]

Another example is the recent and controversial British case *In Re A (Conjoined Twins: Medical Treatment)*.[329] In this case, the Court of Appeal authorized the surgical separation of conjoined twins knowing that one of them would necessarily die during the operation. Taking into account quality of life considerations and the fact that without the surgery both infants would certainly die, the Court concluded that it was in the *best interests* of both infants to undergo the operation that was going to kill one of them. Both France and United Kingdom might well have come to a point where quality of life considerations can be used to justify the active killing of a patient in the same way supported by the personhood theories.

I believe that we must be fully aware of and cautious with such legal and practical developments. Very defective neonates must obviously be protected against any form of discrimination. In this respect, the recognition of their legal personhood could be an illusory fiction if, under the cover of a best interests analysis influenced by moral personhood theories or social perceptions of the concept of "person", their right to treatment was different than the non-handicapped and non disadvantaged persons'

[328] See *supra* Part II, Section B, 3.
[329] *Re A (Conjoined Twins: Medical Treatment)* [2001] 1 FLR 1.

same right. Thus, it is regrettable that courts have always been reluctant to discuss openly the moral concept of "person" and its potential impact on a best interests analysis.[330] By so doing, courts have tried to maintain a clear divide between the law and the social and ethical perceptions of what is a "person". Yet, as demonstrated above, the decision to treat or not to treat very defective neonates is unavoidably influenced by such perceptions. As a result, there is certainly an ambiguity in the way the consequences of legal personhood are defined. In this context, it remains difficult to determine how and to what extent treatment should be given to very defective neonates in order for them to be treated both as full moral and legal persons.

V. CONCLUSION

Modern medical technology has given us the power to sustain and save the lives of very defective neonates. However, significant and vexing ethical and legal questions have surrounded this increasing power. Which preterm, VLBW or malformed neonate is so "defective" that neonatal intensive care should not be provided? This thesis attempted to demonstrate that an answer to this question cannot appropriately be found without considering first the concept and significance of legal and moral "person" and the different perceptions attached to these notions.

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[330] See, for example, the revealing examples of *Baby K., supra* Part III, Section D, 2.1. and note 218, and *Child and Family Services of Central Manitoba v. R.L. and S.L.H, supra* Section B and note 303.

In the legal field, medical technology has certainly "muddied the waters of personhood", "calling into question the once-stable notion of who counts as a living human."[331] However, in cases of treatment or non treatment decisions made on behalf of very disabled children or defective infants, North-American courts have rarely openly challenged the legal and moral personhood of such patients. They have preferred to focus their attention on a best interests analysis and such a standard appears to be adequate.

Nevertheless, in this debate, courts seem to have carefully chosen to evade significant issues linked to the status of defective neonates.

Firstly, despite major concerns about the interpretation of the traditional "born alive and viable" rule used to delineate the beginnings of legal personhood, courts have never been explicit about what could constitute the concepts of "live-birth" and "viability" for very defective neonates. If such concepts delineate the beginnings of legal personhood, the legal status of defective neonates could obviously be challenged on such grounds. Yet, the debate has been limited to the legal status of foetuses. In the United States particularly, in foetal rights and abortion cases, courts have manipulated the "born alive and viable rule" to such an extent that the distinction between the status of late-term foetuses and that of neonates has been blurred. This has occurred to the detriment of legal consistency.

[331] See "What We Talk About When We Talk About Persons", *supra* note 95 at 1768.

Secondly, assuming that neonates are legal persons (whatever their medical condition), courts have rarely considered the potential impact of moral personhood theories on a legal analysis of a defective neonate's best interests that includes quality of life considerations. Yet, this paper has demonstrated that a clear divide between legal personhood and ethical and social perceptions of the concept of "person" is a delusion. Quality of life judgements unavoidably require the resolution, or at least, the discussion of philosophical and ethical matters. Thus, courts should not endorse medical decisions based upon quality of life grounds without discussing the fundamental ethical implications that are involved. Deciding whether the life of a very defective neonate is worth living is an ethical and philosophical judgement that calls for an open and honest discussion about moral personhood theories and their practical impact on a best interests analysis. In any case, the mood of general indignation that surrounds those theories should not deter the courts from further developing and discussing standards that have a direct link with the concept of person. Without doubt, such a debate "could contribute more fully to social dialogue about what it means to be human."[332]

[332] *Ibid.*

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