The moral malaises of modern pediatric medicine

Thèse

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Résumé

Le cadre éthique dominant en médecine pédiatrique est intrinsèquement problématique, car des considérations morales importantes y restent dissimulées. Ce problème correspond bien au déplacement des malaises moraux dans la modernité énoncés par Charles Taylor. En nous référant à Taylor, nous soutenons que la médecine pédiatrique contemporaine et la bioéthique reflètent la théorie morale moderne centrée sur des procédures décisionnelles, sans considération explicite des fondements moraux de telles procédures. L'objectif de cette thèse est d'examiner les préoccupations morales de la médecine pédiatrique contemporaine grâce au cadre philosophique développé par Taylor. Le travail de Taylor a orienté cette recherche (a) *méthodologiquement*, car sa conception de l'herméneutique a servi de cadre d'analyse ; et (b) *substantivement*, car son analyse de la modernité et de la théorie morale a été une référence indispensable. La philosophie herméneutique de Taylor ainsi que son analyse de la modernité sont examinés afin de retracer les *horizons de signification* et les *imaginaires sociaux* dans lesquels la médecine pédiatrique est née et s'est attachée à des orientations morales particulières. Cette approche montre que la médecine pédiatrique apparaît 1) d'abord lorsque les intérêts économiques et militaires de l'Etat le conduisent à valoriser la santé des enfants, 2) ensuite lorsque apparaît une orientation éthique mettant l'accent sur l'enfant lui-même selon le critère du *meilleur intérêt* de l'enfant. Trois malaises moraux ont été identifiés dans la médecine pédiatrique moderne: (a) la convergence du droit et de l'éthique; (b) la conception des enfants comme étant incapables et dépendants ; et (c) la nature ambiguë du concept du *meilleur intérêt*. Nous examinons ces malaises afin de révéler les *horizons de signification* et les *imaginaires sociaux* qui leur ont donné naissance. Un cadre taylorien est également proposé afin d'enrichir la pratique bioéthique

pédiatrique actuelle – *la récupération et le rapprochement herméneutiques* – permettant ainsi l'accordage interprétatif et la réconciliation des considérations morales dissimulées dans le cadre éthique courant. Les implications à l'égard de la recherche ainsi que la pratique et la formation en pédiatrie sont présentées.

Abstract

The dominant ethical framework in pediatric medicine is inherently problematic because important moral considerations are concealed. This problem is congruent with the displacement of moral malaises in modernity articulated by Charles Taylor. Drawing on Taylor's work, I argue that contemporary pediatric medicine and bioethics are reflective of modern moral theory, which is centered on *decisional procedures* without explicit regard for the *substantive moral grounds* that such procedures should relate to. The goal of this thesis is to examine moral concerns in contemporary pediatric medicine through Taylor's philosophical work. Taylor's ideas oriented this examination (a) *methodologically*, as his conception of hermeneutics served as the analytical framework, and (b) *substantively*, by drawing on his analysis of modernity and moral theory. Taylor's hermeneutical philosophy as well as his examination of modernity are reviewed to provide a philosophical framework for tracing the *horizons of significance* and *social imaginaries* within which pediatric medicine emerged and became aligned with particular moral orientations. An operational explicitation of Taylor's hermeneutical approach was developed to examine (a) the early history of pediatric medicine as children's health became valued in light of state and societal economic and military interests and (b) the emergence and ongoing development of the *best interests* standard, a more child-centered ethical orientation. Three moral malaises in modern pediatric medicine were identified: (a) the convergence of law and ethics; (b) the construal of children as incapable and dependent; and (c) the ambiguous nature of *best interests*. These malaises were examined to the retrieve the background *horizons of significance* and *social imaginaries* against which they were shaped. Moreover, a Taylorian framework for the practice of pediatric bioethics is proposed - *hermeneutical retrieval and*

rapprochement - to enrich pediatric practice through interpretive attunement and reconciliation of concealed moral considerations. The implications for future research as well as pediatric practice and education are outlined.

Acknowledgements

This thesis marks the culmination of an extraordinary exploration. Although this exploration started long before my entry into this doctoral program, completing all of the requirements of this program (i.e., coursework, thesis, and numerous other related activities) has enabled me to conduct an investigation that engaged me in so many aspects of my life. Consequently, the number of people that I need to thank is huge, as I have been discussing this work with anyone willing to humor me for many, many years. Needless to say, I cannot list all of the people that have inspired and supported this work.

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Thank you to my family and my friends – especially my mother and late father, my late brother Michael, my daughter Marissa, and my wife Mary Ellen. They have sustained me intellectually and emotionally; and tolerated all of the time, attention, and my everyday DEEP preoccupation (frequently bordering on obsession!!) that this work has required of me.

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This work would not have been possible without the intellectual giant that inspired this project in the first place: Charles Taylor. From my initial point of contact with Taylor's work – over twenty-five years ago - through to the more recent immersion permitted by this thesis, I have had the wonderful experience of shifting into a new worldview – a "Taylorian philosophical anthropology". This has transformed my entire understanding of the human

sciences – for the better. In addition to benefitting from his voluminous body of publications, I am especially grateful toward the many opportunities that I have had to speak with Professor Taylor personally to discuss my questions about various facets of his work. Particularly “impactful”, was my opportunity to work with him directly on a theme issue of the *Journal of Medicine and Philosophy*. I am PROFOUNDLY grateful: Professor Taylor has been tremendously patient and generous toward me!!! Thank you so much!!!

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Abbreviations

HCP: Health care professionals
SI: Social Imaginaries

Frequently Cited Taylor Publications

(See references for complete details)

Taylor, 1985c: Interpretation and the sciences of man.
Taylor, 1989: *Sources of the self: The making of the modern identity*.
Taylor, 1991: *The Malaise of Modernity*.
Taylor, 1992a: *Multiculturalism and the politics of recognition*.
Taylor, 2004: *Modern Social Imaginaries*.
Taylor, 2007: *A Secular Age*.

Introduction[1]

Hospital to pull plug: Mother 'living through hell' as baby to be taken off her life-support system (Gazette, 1994)[2]

A Toronto woman says she's "living through hell" after being told that the Hospital for Sick Children will discontinue ventilator life support for her baby daughter, who's in a deep coma.

Doctors informed Tami Knowles they'll disconnect the life-support system Feb. 3 because baby Kandice's degenerative brain disease leaves her no hope of survival.

Knowles, 27, said she's opposed to the decision but has been given no say in the matter.

"I just don't feel that I, or especially that hospital, should say your daughter is going to die on this date," she said.

"Where are my rights?"

Kandice, born in September, was an alert, happy infant the first three months of her life, said her mother.

But the family noticed around the beginning of December that her eyes wouldn't focus and she would stare at the wall, "like she was in a trance."

She was diagnosed at Toronto's Hospital for Sick Children with a fatal degenerative brain disease.

It's a "defect in the function of the mitochondria – or an inborn error of metabolism" said the hospital spokesman Claudia Anderson.

Opinions from other world renowned hospitals confirmed the diagnosis, Anderson said.

A critical-care physician at the Sick Children's hospital wrote to Knowles this month trying to explain the situation.

"Continuing ventilator support is not in Kandice's best interests," Dr. Desmond Bohn said in his letter.

"We would ask you to understand that this is a medical decision, which is inevitable given the irreversible nature of your child's disease and would ask you to understand why the ventilator support cannot be continued indefinitely."

Bohn said the ventilator was supposed to be stopped last Friday but the date was pushed back two weeks when Knowles protested. He said the baby might not even live until Feb. 3.

Knowles has complained about what she considered to be insensitive handling of the case by doctors at Sick Children's.

"It's just disgusting," she said. "It's like they have no care, no compassion, anything."

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[1] The American Psychological Association reference citation system is used in this thesis because it permits (a) embedded citations of authors, for the convenience of the reader, as well as (b) footnotes to permit required elaborations. This citation system is recognized in several philosophy programs.

[2] This case is used as an illustrative exemplar for the thesis. It reflects a number of common ethical concerns identified in pediatric medicine, which are demonstrated in subsequent chapters through published empirical research. Also, as a media case in the public domain, no permission was required to discuss it for this thesis.

"He (Bohn) walked in like Mr. Joe Cool and said, 'Your daughter is going to die on Friday."
Pediatrician John Watts, a McMaster University specialist in medical ethics, said such decisions are becoming much more common".
"It's the start of a slippery slope," Watts said. "I find it a worrisome trend."
That's because there's less money and fewer resources, Watts said, and hospitals want to put those dollars in a place where they will do some good.
He said he is not familiar with the specifics of Kandice's case, and there may be no alternative.

The Child's *best Interests* and Respect for Parental Authority

Kandice's case is heart-wrenching. It evokes significant compassion toward the difficult circumstances of her life as well as for her family. One can also come to understand the difficult perspectives of the clinicians involved in her care. Although this newspaper report presents a fairly unflattering view of the physician, it is highly plausible that a genuine wish to "do the right thing" was underlying his actions.

Kandice's case is not unlike many cases considered to be ethically problematic in pediatric medicine. It explicitly evokes well documented questions: (1) Which child's life should be sustained with medical technologies? (2) How should such decisions be made? (3) Who should make these decisions?

The American Academy of Pediatrics Committee on Bioethics (AAP, 1994; 1995) and the Canadian Pediatric Society (CPS, 2004) have published statements on consent and decision-making with children. These indicate that, for children who cannot give consent themselves, parents should be responsible for granting permission for treatment while giving great weight to the clearly expressed views of the child when possible.

Decisions regarding children call for the use of the "best interests" standard, weighing the proportional balance of the benefits and burdens related to the various treatment options. These recommendations are consistent with the prevailing bioethical

and legal norms regarding the care of children in North America.[3] These norms are legally recognized in all North American jurisdictions. Although there may be instances where physicians may act in a paternalistic manner, this is generally denounced through hospital complaints procedures, legal proceedings, or through the public media.[4]

Under usual circumstances, parental authority is so well recognized in North America that in cases where physicians disagree with parental wishes, they need to obtain court authorization to provide refused medical care (AAP, 1994; 1995; CPS, 2004).[5] This quasi-absolute parental authority for their children's care is rooted in a broader Anglo-Saxon norm of respect for personal and family autonomy. It is generally held that it is not for the state to decide how families should raise or care for their children, except for cases of suspected child abuse or neglect.[6]

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[3] The emergence of these norms is examined in detail in the *best interests* analysis that follows in chapter 4. They can be traced largely to the *Report on Studies of the Ethical and Legal Problems in Medicine and Biomedical and Behavioral Research* published by the (U.S.) President's Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioral Research (President's Commission, 1983). This Commission sought to address the rising number of ethical controversies emerging in health care practice and research. Ethical norms asserted by this report that are directly relevant for this thesis included: (1) informed consent is required from competent patients; (2) surrogate decision-making is required for incompetent patients (i.e., the surrogate should typically be a family member); (3) parents should ordinarily be the surrogate decision-makers for children who are too young to be legally permitted to consent for themselves (upholding parental and familial autonomy – except for situations where parents are considered neglectful or abusive); (4) medical decisions for incompetent patients and children should be determined according to the treatment option that serves the patient's *best interests*, through a weighing of the benefits and burdens implied by each option.

[4] For example, the Canadian National Film Board released the documentary *Médecine sous influence* (2004) wherein parents voiced their contestations toward physicians who saved their children's lives through resuscitative medical care, which, according to the parents, resulted in severe disability. These parents asserted that they would not have consented to life-sustaining measures if they had been given a choice.

[5] For example, court authorization is commonly sought to administer blood products to children of Jehovah's Witnesses. These situations, along with related legal considerations, are discussed later in the thesis.

[6] For a comprehensive review of contemporary ethical issues in pediatrics, see Miller's (2010) edited book *Pediatric Bioethics*. Several papers from this collection are cited throughout this thesis. Numerous other publications address additional issues. For example, in a general discussion of pediatric bioethics, Miller (2003) has argued that pediatric medicine requires a shift in the ethical approaches that are predominantly used with adults; a shift from *autonomy* to *beneficence*. According to Miller, "beneficent medical decision-making" in pediatrics requires a "therapeutic alliance" between physicians and families and children. A significant body of literature has focused specifically on ethical concerns in neonatology. In their examination of the recent history of the medical care of newborns, Lantos & Meadow (2006) highlighted three principal eras in the United States: (1) the recognition of neonatology as a distinct medical specialty, during which time

Returning to Kandice

With these norms in place, the resolution of Kandice's case would appear fairly straightforward. The decision to provide continued mechanical ventilation or not should be based on her *best interests*; i.e., the treatment option that would provide the greatest benefit in relation to burden should be chosen. On the basis of the widely recognized decision-making norms outlined above, the assessment of Kandice's interests would ordinarily be judged by her parents.

For the purposes of illustration, let us consider two possible courses of action. On the one hand, mechanical ventilation can be withdrawn to allow Kandice to die. On the other hand, it can be maintained on a long-term basis. In the former case, Kandice could benefit from the prevention of long-term daily suffering that can result from her significant physical disability, rendering her dependant on technology to sustain her respiration, and on complete care for all of her physical needs such as feeding, elimination, bathing, and ambulation. However, she would also suffer the "burden" of losing her life, consequently deprived of pleasures that she may be capable of experiencing.

Otherwise, ventilation could be maintained "permanently". She would benefit from a prolonged life, with all of the possibilities it could offer (e.g., receive her family's love,

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parental authority and children's rights in this setting were closely debated and articulated (i.e., late 1960s to the Baby Doe case in 1982); (2) following the Baby Doe case, significant initiatives were undertaken to attempt to develop national standards for treatment decisions regarding newborns; and (3) consistent decision-making criteria and policies were established. In *The Lazarus case*, Lantos (2001) presents a fictitious medical malpractice case in neonatology, drawn from his own medical experience, to examine fundamental ethical concerns in neonatal intensive care such as: standards of care, prognostication, futility, consent, decision-making, and medical errors. Heimer and Staffen (1998) conducted an ethnographic examination of the social organization of responsibility in two American neonatal intensive care units. They highlighted that the responsibilities of parents and HCP toward critically ill newborns are socially produced and sustained, rather than prescribed by ethical and legal norms. For a brief historical overview of medical ethics in neonatology, see Placencia & McCullough (2011). For additional discussions of the challenges involved in assessing a child's best interests in relation to parents' interests, see: Cornfield & Kahn (2012) and Lantos (2006).

nurturance, and comfort). But, this prolonged life would also be arguably severely limited, entailing significant daily suffering and deprivation.

These two treatment options, withdrawal or maintaining mechanical ventilation, involve a comparative weighing of value-laden phenomena or "goods"; e.g., the inherent value of life as a worthwhile good in itself "versus" the potential for "quality" fulfillment of that life (i.e., *sanctity of life* versus *quality of life*).

In the modern West, there exists no agreed upon hierarchy of values to resolve how these goods ought to be weighed in Kandice's case. It is therefore commonly recognized that parents should assess the course of treatment that would serve the child's *best interests*, in light of the family views they wish to cultivate for their family; with the exception of actions that might be regarded as neglectful or abusive toward the child. Parents are required to, and have a right to, "freely" choose whether it is best for Kandice to be ventilated or not.

Questioning the Dominant Ethical Framework in Pediatric Medicine

Despite the development of these norms, why do cases such as Kandice emerge as ethical dilemmas? Is the problem simply a technical legal issue of determining which questions are medical and which are parental? Do they merely involve questions regarding the interpretation of these norms, which at times will require an analysis by the agent designated by society with the ultimate interpretational authority: a court?

In this thesis I argue that cases such as Kandice are inadequately understood and reconciled with the dominant ethical framework in pediatric medicine and bioethics.[7] Such

[7] For the purposes of this thesis, "bioethics" refers the prevalent mode of inquiry that has emerged in modern Western academia and clinical practice for examining ethical questions in the "life sciences". I am

cases frequently demonstrate that "*best interests* determination procedures" result in significant moral residue; involved agents commonly face persisting moral dilemmas or distress.[8,9] This results from dominant procedures that narrowly construe that which is morally meaningful and disregard additional realms of moral life as morally less significant. For example, in a case involving life-sustaining treatments for a child, determining the child's *best interests* unfolds in a context where agents are also striving to be "a good parent" or a "good doctor, nurse, or hospital", among others. A child's interests dwell within a broader moral landscape of additional interests such as family interests, parental interests, sibling interests, clinician interests, institutional and state interests, among others.[10] Moreover, the moral lives of these agents can involve dimensions

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specifically critiquing a division of bioethics that attends to medical problems, which has adopted a primarily *principlist* framework - particularly in North America (Beauchamp & Childress, 2001). Principlism is examined and critiqued more thoroughly in subsequent chapters of this thesis.

[8] For a detailed discussion of "moral distress" in relation to the care of critically ill children, see: Austin, Kelecevic, Goble, & Mekechuk, 2009. In Carnevale (2007), I relate the sense of moral residue that is frequently encountered in pediatric critical care to the tragic choices commonly encountered by clinicians and families; referring to tragedy as depicted in ancient Greek literature. That is, incontrovertible dilemmas where even virtuous agents are drawn into choices and actions that feel morally bad.

[9] Footnote #6 in this introduction outlines selected literature on contemporary ethical issues in pediatrics, highlighting that pediatric medicine involves a wide range of ethical problems, which are commonly inadequately reconciled with current ethical frameworks. This helps justify the need for the investigation conducted in this thesis.

[10] A critical examination of the *best interests* standard in pediatrics is published in a 1997 theme issue of the *Journal of Medicine and Philosophy* (Volume 22 Issue 3), edited by Loretta Kopelman. In the opening commentary, Kopelman (1997a) discusses how the *best interests* standard affects moral and ethical decisions for children; reviewing the uses as well as the criticisms of the *best interests* standard. Downie & Randall (1997) discuss the rights of parents to decide on behalf of infants and young children in terms of the importance of preserving intimate family relationships, rather than in terms of the child's *best interests*, while highlighting legal, ethical, and financial constraints on parental decision making. Clayton (1997) examines the allocation of decision-making authority between parents and physicians for genetic testing in children. De Ville (1997) reviews the problem of who should serve as surrogate decision makers for the children of adolescent parents, calling for a greater level of watchfulness over the competency and decisions of adolescents making decisions for their children, but not definitive enough to conclude that, as a group, they be presumed incapable of making those decisions. Kopelman (1997b) examines a wide range of issues relating to the *best interests* standard. She highlights prominent criticisms of this standard as self-defeating, individualistic, unknowable, vague, dangerous, and open to abuse. Despite these concerns, Kopelman defends this standard by identifying its employment as (a) a threshold for intervention and judgment (e.g., child abuse and neglect rulings); (b) an ideal to establish policies or *prima facie* duties; and, (c) a standard of reasonableness. See Kopelman (2010) for an updated review by the same author.

extending beyond their mere "interests", including for example, rights and obligations as well as socio-culturally transmitted mores.

The dominant ethical framework in pediatric medicine and bioethics is inherently problematic because important moral considerations are concealed, congruent with the common displacement of moral malaises in modernity articulated by Charles Taylor.[11]

I argue in this thesis – in line with Taylor – that contemporary pediatric medicine and bioethics are reflective of modern moral theory, which is centered on *decisional procedures* without explicit regard for the *substantive moral grounds* that such procedures should relate to. Ethical questions refer (implicitly or explicitly) to some ultimate goods that are commonly concealed and unarticulated in modernity. Modern medicine and corresponding ethical frameworks mistakenly rely on a narrow conception of moral life.

Taylor has critiqued modern moral theory for its implicit endorsement of modern naturalism wherein notions of the "good" are relegated to matters of contemporary values. That is, moral sentiments are regarded as subjective human reactions to a presumed neutral objective physical world. This characterizes moral phenomena as "non-real."

Taylor has highlighted that modern Western societies have privileged (a) individualism, (b) instrumental reason, and (c) political atomism as primary goods (Taylor, 1991). This is traced to fundamental features of modern scientific and social revolutions that have assigned a primordial significance to the affirmation of ordinary life and the manipulation of the physical world to serve the ends of humanity.

[11] I acknowledge the numerous debates regarding the definitions attributed to "moral" and "ethical" – which I did not intend to advance in this investigation. For the purposes of clarity of articulation, I use the term "moral" to refer to background or underlying conceptions of the good, right, or just, while "ethical" refers to practice conceptions of the good, right, or just. For example, the former can relate to societal or community values or beliefs, while the latter can refer to conduct or normative statements regarding conduct (e.g., codes of ethics, practice standards).

The goal of this thesis is to examine moral concerns in contemporary pediatric medicine through Taylor's hermeneutical framework and his investigations of modernity. That is, Taylor's work orients this examination (a) *methodologically*, as his conception of hermeneutics serves as the analytical framework for the thesis, and (b) *substantively*, drawing on his analysis of modernity and moral theory to inform this investigation of pediatric medicine.

This investigation relates to a broader body of literature that has critiqued the "dominant ethical paradigm" within medicine and bioethics in general, and pediatric medicine and pediatric bioethics in particular.[12] Indeed, some writers have already argued that hermeneutics can make important contributions to bioethics.[13] However, these papers have limited their focus to the development of novel approaches to *clinical* ethical

[12] Some of these critiques are reviewed in chapter 5.

[13] For examples, see: Carson (1990; 2011); Daniel (1986); Svenaeus (1999; 2003); Thomasma (1994); and Betan (1997). Carson (1990) criticizes the common approach to bioethics as tethered to a social contract view of the doctor-patient relationship that is largely incompatible with experiences of illness and care and as a formalist doctrine that lacks critical edge and tends toward "accommodationism". He argues for a hermeneutical alternative that interprets moral experience by means once associated with the rhetorical arts: practical reasoning, hermeneutics, casuistry, and thick description. In a later work, Carson (2011) discusses Taylor's retrieval of an expressivist understanding of persons and of language as constitutive of meaning as important insights for restoring moral connectedness between patients and physicians. Daniel (1986) proposes a hermeneutical model as an orientation to clinical decision-making, considering a patient is analogous to a literary text that can be interpreted on four levels: (1) the literal facts of the patient's body and the literal story told by the patient, (2) the diagnostic meaning of the literal data, (3) the praxis emanating from the diagnosis, and (4) the change effected by the clinical encounter in both the patient's and clinician's life-worlds. Svenaeus (1999) calls for a shift away from a view of medicine as an assembly of applied scientific theories and technologies to a view of medicine as a practice of healing with a central structure that is the meeting between the physician and patient – this meeting is construed as a clinical hermeneutics. Drawing on the hermeneutic philosophy of Gadamer, Svenaeus argues how the physician and patient strive to reach a common interpretation of the clinical problem. Svenaeus (2003) also considers medical practice as an interpretative meeting between physician and patient, wherein the good physician comes to know what to do for a particular patient at a particular time through hermeneutical interpretation. Thomasma (1994) regards clinical ethics and medical decision-making as a unitary hermeneutics, arguing that clinical ethics interprets the clinical situation in light of a balance of values that guide the decision-making process while also contributing to the very weighting of those values. The clinical case originates ideas about which value ought to predominate as well as the origin of interpretive rules that can be used in other cases. Betan (1997) articulates a hermeneutic model for psychotherapists that recognizes the context of the therapeutic relationship and the therapist's subjective responses as fundamental considerations in the interpretation and application of ethical interventions.

problems.[14] They have not advanced hermeneutics as a framework for a *philosophical* (rather than clinical) examination of moral concerns in contemporary medicine in general, and in pediatrics in specific.

Thus, this thesis makes original contributions in articulating (a) a hermeneutical philosophical methodology for examining moral problems in medicine as well as (b) a philosophical analysis of the moral malaises of modern pediatric medicine.

It should be highlighted that this investigation is not a critique of Taylor's philosophy. Many significant examinations of Taylor's work have already been conducted; many of which are cited in this thesis.[15] Rather, this investigation builds on some of

[14] Gadamer's *The Enigma of Health* (1996) is a notable exception. In this collection of essays, Gadamer challenges the dominant conception of medicine as disproportionately centered on science and technical mastery. He argues for a greater recognition of the "artful" dimension of medical practice, which involves hermeneutical interpretation and judgement.

[15] For example: Abbey, 2004a; Benner, 1994a; Carnevale & Weinstock, 2011; Gagnon, 2002; Laforest & de Lara, 1998; Pélabay, 2001; Redhead, 2002; Smith, 2002; Tully, 1994. Published examinations of Taylor's work provide further discussions and critiques of his ideas. The selected examples cited in this thesis refer primarily to book form publications, because they offer more substantive examinations. There exist, however, a very large number of additional papers and journal theme issues, as well as additional books. The "investigations of Taylor" cited in the thesis are selected primarily for illustrative purposes. The cited works should not be considered exhaustive, as it is not the primary aim of this thesis to present a comprehensive critique of Taylor's ideas. Some commentators on Taylor's work have focused primarily on "disseminating" his large body of work, bringing together specific or general aspects of his work in a single integrated whole, offering selected syntheses and interpretations. For example, Abbey (2000) presents an introduction to Taylor's ideas, focusing primarily on his work on moral theory, selfhood, political theory, and epistemology. Abbey draws out ideas that overarch Taylor's writings while also addressing some of the published critiques of Taylor's work. Smith (2002) has published an exemplary overview of Taylor's "philosophical anthropology", reviewing his work on the human sciences, personal identity, language, moral life, multiculturalism, and secularization. Smith presents a critical synthesis of Taylor's ideas in these domains. Some work has articulated Taylor's work in other languages (e.g., French) to promote the circulation of Taylor's ideas among additional scholars and readerships. For example, Gagnon (2002) has published a highly comprehensive French-language overview of Taylor's work, structured in terms of Taylor's philosophical and moral orientation, as well as well as his work on ethics and democracy. Pélabay (2001) has prepared a French-language discussion of selected arguments in Taylor's political philosophy. She examines Taylor's politics of recognition, in relation to his work on freedom and tradition, equality and difference, individualism and community, with a particularly extensive examination of Taylor's notion of *deep diversity*. A number of published works offer further insight, interpretation, and critique of Taylor's work. For example, Redhead (2002) has published a critical discussion of aspects of Taylor's political philosophical analysis of Quebec and Canada. Redhead highlights what he considers problems in Taylor's notions of *deep diversity* and *political fragmentation*, while also examining other aspects of Taylor's philosophy such as self-interpretation, and catholic modernity. Redhead offers re-articulations that he argues could help resolve these problems. Mulhall (2004) has outlined the intellectual links between Taylor's moral theory and political theory; particularly examining atomism, negative freedom, and politics of recognition. The collection edited by

Taylor's most highly supported examinations of hermeneutics and modernity in pushing his work further by adapting it for a philosophical analysis of modern pediatric medicine (i.e., in chapters 3 to 5) and to propose a re-conception of the practice of pediatric bioethics (i.e., in chapter 6); while also advancing Taylor's own work by attempting to articulate an operationalization of his hermeneutical "methodology" (i.e., in chapter 2).

Why the Philosophy of Charles Taylor?

Why was the philosophy of Charles Taylor selected to orient the analysis undertaken in this thesis? This choice was based on several factors. As described above, persistent moral concerns in pediatric medicine have been described, for which the dominant framework in pediatric bioethics appeared inadequate. This ongoing problem sparked my search for an alternative moral and ethical orientation.

I had my earliest encounter with Taylor's work in the 1980s, through the research of Patricia Benner. Benner is an internationally acclaimed nursing researcher at the University of California in San Francisco who has articulated a qualitative research methodology for the health sciences, drawing heavily on Taylor's hermeneutical philosophy (Benner, 1994a).[16] This motivated me to read Taylor's work directly – stimulating my interest in

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Laforest and de Lara (2001) reviews a number of Taylor's philosophical arguments in relation to "intellectual traditions of the French language". This includes examinations of Taylor's hermeneutics, political theory, epistemology and philosophical anthropology, including a contribution by Taylor himself. *Philosophy in an age of pluralism: The philosophy of Charles Taylor in question*, a collection edited by Tully (1994), presents a strongly comprehensive critical review of Taylor's work, followed by Taylor's direct replies to his "critics" (Taylor, 1994a). This book also lists an extensive bibliography of Taylor's earlier published books and papers (Tully, 1994, 258-264). Orlie (2004) discusses how Taylor's philosophy relates to feminist discourse. This relation has been scarcely reviewed; indeed, Taylor's own references to feminist thought have been limited. Orlie argues that Taylor's work can help advance feminist inquiry. Abbey (2004b) has highlighted that some ideas within Taylor's work would appear to readily intersect with feminist thought, such as embodied knowing, as well as the critique of the reification of science and atomistic individualism. Additional critical discussions of Taylor's work are cited throughout the thesis in relation to particular fields of inquiry.

[16] Benner subsequently published a leading articulation of hermeneutical approaches to empirical research; i.e., *Interpretive phenomenology: Embodiment, caring, and ethics in health and illness* (Benner, 1994a).

both his philosophical orientation in general and his analysis of modernity in specific. My reaction to this early reading is best characterized by a quote by Jeremy Webber (University of Victoria legal scholar), while he was speaking at a 2012 conference in Montreal to celebrate Taylor's eightieth birthday, "After I first read Taylor's *Interpretation and the Sciences of Man*, the whole world looked different to me".[17] This was the same for me. I had a series of "aha" moments in reading Taylor's conception of the human sciences, critique of contemporary moral theory, and the malaises of modernity. Richer ways of understanding pediatric medicine were illuminated, as I had worked clinically in pediatrics since the mid-1970s as a pediatric critical care nurse. I saw opportunities for novel understandings – yet very little work had related Taylor's ideas to clinical problems to date. I was further motivated by the clearly significant importance of Taylor's work in contemporary philosophy; his work was highly acclaimed through awards and a growing number of books devoted to his philosophy. Moreover, Taylor's presence in Quebec, providing opportunities for direct discussion with him, consolidated the decision to work with his ideas.

As this project was taking shape, it became readily apparent that there were a number of additional problems in contemporary medicine that could benefit from Taylorian investigations, yet were beyond the scope of this thesis.[18] I therefore spearheaded, in

[17] Several Quebec university departments and various partners organized a conference in Montreal to celebrate Taylor's 80th birthday, inviting twenty-seven paper presentations to discuss a wide range of Taylor's work; followed by Taylor's commentaries on each paper. The conference took place on March 29-31, 2012. The conference program is posted online [http://www.creum.umontreal.ca/IMG/pdf_prog_final.pdf] along with audio recordings of the proceedings [http://www.creum.umontreal.ca/taylor/].

[18] Taylor himself has scarcely addressed modern medicine in his writings, with two noteworthy exceptions: (a) a discussion of cultural and acultural conceptions of modernity that describes modernity as a movement from one constellation of background understandings to another that repositions the self in relation to others and the good (see: *Two Theories of Modernity*, Taylor, 1995a) and (b) a political philosophical examination of "caring" in medicine in which he reviews the impact of procedural liberalism – the ways in which caring is undermined by bureaucratic rule (see: *Philosophical Reflections on Caring Practices*, Taylor, 1994b).

collaboration with philosopher Daniel Weinstock, a parallel project to publish - in the *Journal of Medicine and Philosophy* - a collection of papers examining epistemological, ontological, moral, and political philosophy problems in medicine, in light of Taylor's philosophy (Carnevale & Weinstock, 2011).[19]

Plan for the Thesis

In chapter 1, I outline Taylor's hermeneutical philosophy. This requires a discussion of the shifts in philosophical orientations in the human sciences that preceded Taylor's work, to set the "intellectual landscape" within which Taylor's ideas emerged. Taylor has argued that a hermeneutic framework cannot be understood merely as a set of analytical techniques. I discuss Taylor's moral framework and hermeneutical "method" as a particular line of thought emerging out of the hermeneutical human sciences. Moreover, Taylor's examination of modernity is discussed in detail, including his review of the "malaises of modernity". Taylor's work in this domain provides a substantive moral groundwork against which contemporary phenomena – such as modern pediatric medicine – can be analyzed. In line with Taylor's socio-historical hermeneutical philosophy, pediatric medicine cannot be examined in a vacuum. It is important to trace the *horizons of significance* and *social imaginaries* against which pediatrics emerged and became aligned with particular moral orientations. Taylor situates the moral life of agents in modernity within a contemporary horizon where the ultimate grounding of the moral life has been concealed by espousing presumably neutral ethical decisional models. He has advanced a philosophical outlook that

[19] This theme issue of the *Journal of Medicine and Philosophy* (Carnevale & Weinstock, 2011) includes an introductory paper by myself and Daniel Weinstock that provides an overview of Taylor's ideas, followed by papers by Hubert Dreyfus, Patricia Benner, Gilles Bibeau, Carl Elliott, Natalie Stoljar, Ronald Carson, Dawson Schultz and Lydia Flasher, Laurence Kirmayer, and Daniel Weinstock. The final piece is an interview discussion with Taylor that examines several issues raised in the theme issue (Taylor, Carnevale, & Weinstock, 2011).

resists dominant "proceduralist" models, continually seeking to understand the moral horizon and *social imaginary* within which moral concerns are situated.

Chapter 1 draws primarily on Taylor's works more directly aligned with the focus of this thesis, including his examinations of epistemology and ontology in the human sciences, moral philosophy, and modernity. Much of his political philosophical work was not regarded as directly applicable,[20] with the exception of portions of his analysis of multiculturalism. Taylor's "rapprochement" is adapted in my formulation of a practice framework for pediatric bioethics in chapter 6. *A Secular Age* (2007), Taylor's most recent "opus magnum" is not explicitly related into the analysis for this thesis, because it was published at a time when the "Taylorian" framework for the thesis was largely developed and some of the preliminary examinations of pediatric medicine were already underway. The significant amount of time required to gain a strong grasp of this voluminous work did not seem necessary, given that some of Taylor's earlier examinations of secularization were already accessible through his earlier analyses of modernity, which have been incorporated into this thesis.

In chapter 2, I outline an operational explicitation of Taylor's hermeneutical approach to articulate the "Taylorian methodology" used in this thesis. This operationalization of Taylor's hermeneutical philosophy is another innovative contribution of this thesis.

Chapter 3 presents an analysis of the early history of pediatric medicine. This starts with a sketch of the early social construction of childhood, leading to the medicalization of infant mortality and childhood health and development, with the "birth" of pediatric

[20] Taylor has also published important examinations of the philosophy of Georg Wilhelm Friedrich Hegel. This work is not reviewed in this thesis as it was not essential for this investigation.

medicine. This was initially grounded on a utilitarian-oriented moral foundation, where the well-being of infants and children became valued as a support for state and societal economic and military activity. In the middle of the 1900s, a more child-centered moral orientation emerged, anchored on the *best interests* standard.

In chapter 4, I articulate a detailed examination of the *best interests* standard; documenting its early emergence in law, followed by its adaptation into pediatric medicine. Three notable issues relating to moral concerns in pediatric medicine are highlighted and discussed in terms of the challenges that they imply.

These three issues are further examined in chapter 5 as three principal moral malaises in modern pediatric medicine: (a) the convergence of law and ethics; (b) the construal of children as incapable and dependent; and (c) the ambiguous nature of *best interests*. These malaises are examined to the retrieve the background *horizons of significance* and *social imaginaries* against which they were shaped.

In chapter 6, I present a Taylorian framework for the practice of pediatric bioethics: a framework for *hermeneutical retrieval and rapprochement*. This framework is designed to enrich pediatric practice through interpretive attunement and reconciliation of commonly concealed moral considerations.

In the conclusion, I present a synthesis of the contributions developed in the thesis, along with an outline of implications for future research as well as pediatric practice and education.

Chapter 1: Hermeneutics and the Philosophy of Charles Taylor

Introduction

In this chapter, I discuss Taylor's "methodological" contribution to the philosophical analysis of moral problems: *hermeneutics* – the methodological framework used for this thesis. Hermeneutics cannot be understood simply as a set of techniques. Hermeneutics is rooted in an underlying ontology and epistemology – a philosophical re-conception of the nature of phenomena and how they can be understood.

Given the significant scope of this chapter, it is divided into three major sections. In the first section, I outline shifting perspectives in the human sciences and the corresponding emergence of hermeneutical inquiry in philosophy, to situate Taylor's orientation historically and intellectually.

In the second section, I review Taylor's moral framework and hermeneutical approach as a particular line of thought emerging out of the hermeneutical human sciences. Taylor's moral framework provides several important concepts that help orient the analysis of pediatric medicine conducted in this thesis.

In the third section, substantive aspects of Taylor's hermeneutical analyses of modernity are reviewed. Specifically, Taylor's examination of moral malaises as well as shifting conceptions of the self are discussed. This discussion helps illuminate the social context within which modern pediatric medicine emerged, while also illustrating Taylor's hermeneutical methodology through demonstration.

Section I

Shifting Perspectives in the Human Sciences

Understanding Taylor's hermeneutical framework requires an examination of the intellectual landscape within which it emerged. The following discussion of the historical emergence of hermeneutics outlines how this can be traced to fundamental shifts in the human sciences. This tracing of the "sources" of hermeneutics informs the subsequent discussion of specific ideas articulated by Taylor. Moreover, this examination of hermeneutics in light of its corresponding historical context is consistent with Taylor's historically-centered conception of hermeneutics.

It should be noted that hermeneutical inquiry is a vast field of scholarship. The "genealogy" traced here is restricted to the most significant influences on the emergence of Taylor's philosophical orientation.[1] Moreover, some portions of the review in this section are very brief, in the interests of succinctness and because it is not a goal for the thesis to undertake an analysis of the historical foundations of hermeneutics. This review is intended primarily to orient the subsequent discussion of the "emergence" of Taylor's ideas. There is no intention to discount the importance of the many hermeneutical works that have been excluded.

[1] For a more detailed review, see Thouard (2011). Thouard's edited collection of papers reviews hermeneutical examinations of various foundational themes such as understanding, interpretation, human sciences, analysis of texts, and hermeneutical knowledge. The collection includes a translated version of Taylor's *Interpretation and the sciences of man*, an excerpt from Gadamer's *Truth and Method*, along with contributions from Dilthey, Simmel, and Engel, among others.

> Since its emergence in the seventeenth century, the word *hermeneutics* has referred to the science or art of interpretation (Grondin, 1991/1994, p. 1).

Contemporary hermeneutics is most strongly related to the work of Schleiermacher, Dilthey, Heidegger, and Gadamer.[2] Although, philosophical examinations of interpretation have existed since antiquity in some form or another (e.g,, Aristotle's *De Interpretatione*), Grondin points out that in the ordinary sense, *philosophical hermeneutics* "refers to the philosophical position of Hans-Georg Gadamer" (Grondin, 1991/1994, p. 2). Gadamer is recognized as a most influential thinker in the development of philosophical hermeneutics, and will thus figure prominently in sections of this chapter.[3]

The human sciences faced a methodological challenge in post 19th century thought because they had come to see themselves as analogous to the natural sciences. In the English tradition, Mill regarded the human sciences as seeking regularities and conformities to law that would make it possible to predict individual phenomena and processes. For Gadamer, the human sciences do not seek to understand individual cases as instances of a universal rule. Rather, a phenomenon should be understood as a unique thing in itself – how a person or persons happened to become what they are.[4]

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[2] Ricoeur also developed a hermeneutical framework, which differed from that of Gadamer (example: Ricoeur, 1991). This discussion of historical context will focus primarily (but not exclusively) on Gadamer as his hermeneutics established a highly dominant position with which Taylor's hermeneutics is highly aligned, without any intention of diminishing the importance of Ricoeur's outlook. Ricoeur has directly intersected with some of Taylor's work. Some of this work is cited later in this chapter in the discussion of Taylor's *Sources of the Self*.

[3] In addition to articulating his own hermeneutical framework, Gadamer's *Truth and Method* (1960/1994) also presents one of the most recognized historical accounts of the "evolution" of hermeneutic philosophy in the human sciences, which strongly informs the discussion presented in this section.

[4] Although hermeneutical orientations to the human sciences emerged in contrast to outlooks that were more closely aligned with the natural sciences, many schools of thought in the human sciences have followed the latter to the present day. Indeed, a diversity of theoretical orientations are employed in this domain. Some scholars, such as Lincoln & Guba (2000) have argued that there exists a diversity of "paradigms" in the human sciences, drawing on Kuhn's (1970) important concept for distinguishing intellectual outlooks. That is, some orientations appeal to fundamentally distinct ontological presuppositions about the human sciences and how these can be understood epistemologically and methodologically. These distinctions are commonly expressed in terms of polemic oppositions relating to: objectivism/subjectivism, explanation/understanding, positivistic appeal to observables/interpretation, individualism/holism, among others. Two prominent poles

Although he distinguished the human sciences from the natural sciences, Dilthey was significantly influenced by the latter, embracing the "spirit" of the natural sciences and "objective" scientific distancing from the phenomenon of interest (Dilthey 1991; 1996; 2002). This inferior characterization of the human sciences was rejected by "German classicism" as it contested Enlightenment *rationalism*. Rather, *humanism* was embraced in the 19th century, centered on the concepts of self-formation, education, and cultivation (i.e., *Bildung*). The early meaning of *Bildung* related to the external form of a thing that was regarded as "natural". This has now come to signify the idea of culture – in particular, the developing of one's natural capacities.

The human sciences orientation appealed to the *sensus communis* – a special kind of "common sense", resembling the practical wisdom of *phronesis* described by Aristotle. This involves a capacity to grasp a situation in a manner that cannot be prescribed by the rational concept of knowledge. This does not refer to "the abstract universality of reason

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have emerged: on the one hand, a positivistically rooted explanatory objectivism that draws on ontological and epistemological frameworks from the natural sciences, while on the other hand a hermeneutically-oriented interpretive subjectivism that is centered on understanding. Proponents of the first "paradigm" argue that the human sciences can and should subscribe to the scientific models of the natural sciences, given the extraordinary successes of the latter, favoring an epistemology that draws on measurement, quantification, the formulation of exact laws, and the verification of explanatory hypotheses through experimental methods. These proponents include Bunge (1998; 1999), Harris (1979), Thurstone (1928), Tolman (1932), and Watson (1919), among others. The second "paradigm" assumes that phenomena in the human sciences are shaped by the human agents that identify these phenomena, incontrovertibly relying on interpretations that are in turn shaped by the particular "thought styles" employed (to borrow a term from Hacking, 1985). These proponents include Gaines (1992), Geertz (1973), Kleinman (1988), Packer & Addison (1989), and Rosaldo (1993), among others. For the purposes of illustration, I have characterized this ongoing debate polemically; however, I acknowledge that many outlooks that have developed within the human sciences do not fit neatly within either "extreme" of this polemic or may draw on aspects of either pole. Moreover, some diverse outlooks have emerged even within the "extreme" poles. The two paradigms described above should not be considered homogenous. For example, Hollis (1994) has attempted to demonstrate that these debates can be further "complexified" by contrasting objectivism/subjectivism and individualism/holism through an orthogonal four-quadrant constellation of these outlooks. This gives rise to four (not two) discernable paradigms for the social sciences: objectivist-individualist, objectivist-holist, subjectivist-individualist, and subjectivist-holist. Berthelot (2001) has tried to address these epistemological/ontological polemic divides by proposing a third intermediate view - a nonreductionistic rationalism that strives to identify constitutive and functional rules for social phenomena. Valade (2001) and Ogien (2001) have published thorough examinations of the problem of holism and individualism in the human sciences.

but the concrete universality represented by the community of a group, a people, a nation, or the whole human race" (Gadamer, 1960/1994, p.21). This emphasizes the "common" in common sense – highlighting its social dimension. *Sensus communis* also implies an ethical dimension – grasping with a moral control that distinguishes what should be done from what should not be done. There is something compelling about grounding the human sciences on the concept of *sensus communis*, rather than theoretical reasoning, which cannot govern the human passions nor adequately advance our understanding of humanity. However, this tradition of thinking has been displaced in contemporary times by the methodological thinking of modern science.

This perspective in the human sciences, shifting toward a hermeneutic conception of *Bildung* and *sensus communis*, set the stage for an epistemological transition to hermeneutics.

Understanding, Interpretation and Hermeneutical Philosophy

The hermeneutical approach to understanding and interpretation initially developed along two different outlooks: (1) *theological hermeneutics* which was oriented toward the interpretation of biblical texts; and (2) *philological hermeneutics* oriented toward classical literature and the understanding of linguistic practices. In both cases, hermeneutics involved an attempt to uncover concealed meanings from the texts in question.

Luther's theological hermeneutics (aiming to direct the Reformation understanding of the Bible toward individual persons) emphasized the significance of the *context* of the text to be understood – the text could not be understood in isolation. This corresponds with some approaches to linguistic analysis, whereby a word or a sentence could not be

understood without consideration of the broader text (paragraph, page, chapter, etc.). Similarly, historical analysis should rely on such contextual review.

The initial development of interpretation as a methodology is attributed to Schleiermacher. Although he was a theologian and never actually published a philosophical account of his hermeneutical framework, his work advanced hermeneutics by demonstration. Schleiermacher challenged the philological approach to interpretation, which he considered as wrongfully centered on techniques. Rather, he attempted to search beyond the texts themselves, focusing his interpretation on the understanding of thoughts. For Schleiermacher, understanding involved a coming together and arriving at a shared understanding – an agreement – regarding the subject matter. He defined hermeneutics as the art of avoiding misunderstandings, bringing to light the truth embedded within a text.

Schleiermacher complemented the grammatical sense of interpretation with *psychological interpretation*, which was taken up further by other interpretivists, namely Dilthey. Psychological interpretation involves putting yourself within the way of thinking of the author. Although such thinking is highly individual, it can be understood because of a pre-existing bond among all persons – a manifestation of universal life. Interpretation should lead to an understanding of which the writer may have been largely unconscious.

Dilthey is credited for his elaboration of a historical hermeneutics (Dilthey, 1991; 1996; 2002).[5] He developed a logical analysis of history wherein detail could only be understood in terms of the whole and the whole could only be understood in terms of its detail – an orientation drawn from romantic hermeneutics. Contrary to Hegelian idealism, Dilthey asserted that ideas are only imperfectly represented in history. Therefore philosophy needs to be replaced by historical research in order to enlighten man's

[5] Taylor subsequently builds on this view, as history forms a central focus of his own hermeneutics.

understanding of himself and where he stands within the world. Historical analysis uncovers a continuity such that the *historically real* can emerge according to the laws of succession, where events are understood in terms of what has preceded. Historical coherence is formed by an unconscious teleology that excludes the insignificant from this coherence.

Dilthey sought to create a new epistemology – being concerned about how the historical school positioned itself *between* the idealism philosophy of Kant and Hegel and that of experience, where the "pure science of reason" was extended to the historical sciences. For Dilthey, experience in the human sciences is quite different from experience in the natural sciences. The historical world is not based on facts taken from experience but rather our inquiry must draw on an inner historicity belonging to experience itself. Experience is a "living historical process" that fuses memory and expectation into a whole. The historical world to be understood is always constructed by the human mind. *Experience* is to be the ultimate ground for understanding the historical world – experience understood as an indivisible whole of *act* (of becoming conscious) and *content* (that of which one is conscious).

Dilthey's epistemology shifts the focus from the coherence of an individual's experience to *historical coherence* that is beyond individual consciousness. This involves a shift from a psychological to a hermeneutical foundation for the human sciences. However, this raises an important problem. How can a historical coherence (that no individual is conscious of) be understood? First, this involves a move away from the causal explanation employed in the natural sciences to an epistemology of understanding and expression.

Phenomenological investigation reveals that what emerges is not the outcome of causal forces but rather an intelligible whole – a structural continuity – that can be

understood in itself regardless of any system of cause and effect. Dilthey referred to this whole as *significance*.

Dilthey examined the problem of how infinite historical understanding can be possible for a finite human nature or mind. Through the use of comparative methods, it is possible to rise above individual experience and apprehend "universal truths."[6]

For Dilthey, knowledge exists in life itself, wherein it is unreflectively connected with experience. A reflective analysis requires a shifting out of one's own goals – striving for a comprehension of stability through contemplation and practical reflection. Dilthey saw a commonality between the natural and human sciences, both seeking to rise methodologically above the realm of individual subjective understanding. He guarded against relativity by striving toward totality.

Husserl argued that, for phenomenological inquiry, prior modes of understanding should be *bracketed*. Experience is examined collectively as a form of *transcendental reflection*. Every experience has implicit horizons of before and after, fusing with the continuum of the experiences present in the before and after to form a unified flow of experience.

Husserl implicitly relied on the notion of *horizon* to account for how systems of meaning merge into a continuity of the whole (1931/1960; 1936/1970). In contrast to the concept of world conventionally understood within the natural sciences, Husserl developed the concept of *life-world*. Here, persons are seen as immersed in a transient world – in a constant movement of relative validity wherein the world is anchored in a communal subjectivity.

[6] Gadamer (1960/1994) subsequently criticized Dilthey on this view, for this comparison presupposes that the knowing subject has the capacity to understand both things contemporaneously. How can consciousness rise above its own relativity? Consciousness is always immersed in a particular historical context.

These Continental schools gave rise to an alternative philosophical orientation to the then dominant neo-Kantianism. Heidegger's commitment to existential philosophy within a hermeneutic orientation brought forth a novel ontological conception of interpretation and understanding – linking the pursuit of understanding to underlying concealed existential questions (Heidegger, 1962). This could only be "brought to light" through hermeneutical interpretation, a search for the "primordial signification" of an expression – an "analytic of the existentiality of existence".[7] However, in his principal treatise *Being and Time*, Heidegger devoted only half a page to a discussion of his sense of hermeneutics – providing little explication of what he had in mind (Heidegger, 1962).

Heidegger criticized Husserl's "hermeneutics of facticity" (eidetic phenomenology) for its preoccupation with the distinction between fact and essence. Rather, phenomenology should be ontologically grounded, examining the facticity of *Dasein* – the existential basis of being. For Heidegger, the meaning of being and objectivity can be made intelligible and demonstrated solely in terms of the temporality and historicity of Dasein (Heidegger, 1962).

Heidegger sought to reorient philosophy toward a Greek antiquity conception of *being* and *time* (1989/1999). That is, there is an important distinction between *being* and *beings* (the latter referring to the more objectivist conception), which has been forgotten by Western philosophy (according to Heidegger) until Nietzsche.[8] For Heidegger, understanding implies an existential realization of Dasein as *being-in-the-world*; wherein "world" assumes a special phenomenological signification.

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[7] Heidegger's "bringing to light" resembles the hermeneutic process of *retrieval* subsequently developed by Taylor (1989).

[8] "Forgotten" phenomena ("concealed" for Heidegger) are the focus of hermeneutical analysis, seeking to bring them to consciousness or "unconceal" them – or "retrieve" them for Taylor.

Gadamer's Hermeneutic Philosophy: *Truth and Method*

Gadamer highlighted that the phenomenological shift implied a different-looking hermeneutics of the human sciences – toward which *Truth and Method* (1960/1994) is devoted. Understanding does not refer to a methodological concept but rather the process of understanding as "an inverse operation that simply traces backward life's tendency toward ideality. Understanding is the original characteristic of the being of human life itself" (Gadamer, 1960/1994, p.259). Understanding is necessarily rooted in historical understanding (within a Heideggerian historicity). Gadamer built on Heidegger's ideas and brought forth what is commonly regarded as the most thoroughly developed philosophy of hermeneutics.

Gadamer examined Heidegger's phenomenology by discussing the hermeneutic circle. The circle provides a possibility for knowing whereby popular conceptions are displaced so that the structure of the things themselves can be discovered.

> All that is asked is that we remain open to the meaning of the other person or text. But this openness always includes our situating the other meaning in relation to the whole of our own meanings or ourselves in relation to it (Gadamer, 1960/1994, p. 268).

This involves being reflectively aware of one's biases and preconceptions in order to fully grasp the otherness (i.e., alterity) of that which needs to be understood. Gadamer further examined these prejudices as potentially resulting from (a) human authority or (b) overhastiness – rather than arriving at one's own understanding. For example, the Enlightenment criticized the dogmatic tradition of Christianity that sought to assert one authoritative reading of the Bible, rather than seek a rationally disciplined prejudice-free interpretation.

However, Gadamer also highlighted that understanding itself is to be thought of as

bound within tradition. An interpretation can never step outside of tradition.[9] Historical consciousness is always regarded as situational. We are conscious within a situation that will always affect what questions we consider worthwhile and the solutions that we can generate. Consequently, historical understanding is never complete but always in flux across situations.[10]

Hermeneutic interpretation requires the understanding of the whole in terms of the parts and the parts in terms of the whole. This is evident in the learning of languages, whereby an entire sentence needs to be created in order to understand the significance of its parts. Heideggerian hermeneutics involves forward and backward reading of texts until they are completely understood. This work also involves the realization of a tension between familiarity and strangeness of a text as a historical traditional object. Hermeneutics is concerned with the "in-between" of the familiarity and strangeness.

Gadamer regarded a situation with a viewpoint that necessarily limits that which can possibly be viewed. This relates to his concept of *horizon*: "the range of vision that includes everything that can be seen from a particular vantage point" (Gadamer, 1960/1994, p.302).[11] Historical consciousness is affected by this horizon, but also involves being aware of the boundaries of this horizon, and what might lie beyond it. As our consciousness considers other historical horizons, it is not roaming into alien disconnected domains, "instead, they together constitute the one great horizon that moves from within and that, beyond the frontiers of the present, embraces the historical depths of our self-consciousness" (Gadamer, 1960/1994, p.304).

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[9] However, this does seem to contradict the Husserlian phenomenological principle of bracketing.
[10] The significance of history in hermeneutical analysis, previously articulated by Dilthey, is further developed by Gadamer, to be subsequently elaborated even further by Taylor.
[11] The notion of "horizon" is subsequently elaborated by Taylor into "horizons of significance", a concept that is central to Taylor's moral framework.

> Transposing ourselves consists neither in the empathy of one individual for another nor in subordinating another person to our own standards; rather, it always involves rising to a higher universality that overcomes not only our own particularity but also that of the other (Gadamer, 1960/1994, p.305).

Gadamer was laying the ground for his notion of *fusion of horizons*: the human capacity to transform one's own horizon through the process of understanding an *other* – given that these (sometimes apparently disparate) horizons converge in terms of an overarching horizon. "*[U]nderstanding is always the fusion of these horizons supposedly existing by themselves*" (italics in original text; Gadamer, 1960/1994, p.306). Through understanding, these horizons are continually being fused and transformed.[12]

In his examination of the significance of understanding and interpretation in hermeneutics, Gadamer highlighted the importance of *application*. In order for a law or a text to be understood historically, it needs to be understood at every moment and situation within which it is presented. Understanding implies an understanding of its application.

This view of understanding where something universal is applied to a particular situation is related to Aristotelian ethics. For Aristotle, "ethics" is based on practice and "ethos." This is not like "physis" where the laws of nature operate. Rather, ethical conduct relies on human institutions and modes of behavior that are "mutable."

> For moral knowledge, as Aristotle describes it, is clearly not objective knowledge – i.e., the knower is not standing over against a situation that he merely observes; he is directly confronted with what he sees. It is something that he has to do (Gadamer, 1960/1994, p. 314).

Aristotle distinguished practical knowledge (*phronesis*) from theoretical knowledge (*episteme*) wherein the latter is represented by a model of mathematics (Aristotle, 1934). Theoretical knowledge is universal, unchangeable, and supported by proof. In contrast,

[12] Taylor built on Gadamer's "fusion of horizons" in developing his notion of "rapprochement" in relation to cross-cultural understanding (Taylor, 1992a), which is discussed in chapter 6.

practical knowledge and the human sciences are centered on man and what he knows about himself as an acting being, including his moral understandings. Practical knowledge serves to govern his action. Practical knowledge resembles technical skill (*techne*) in that the craftsman who knows how to make various things *applies* this skill to a particular task. On the other hand these types of knowledge are different because experience is not sufficient for guiding moral action, "man is not at his own disposal in the same way that the craftsman's material is at his disposal" (Gadamer, 1960/1994, p.316). Practical knowledge implies a unique kind of knowledge – a self-knowledge.

Gadamer pointed to legal hermeneutics as an exemplar of his practice of interpretation. Rather than construing understanding as a method of objective science (as many models of historical hermeneutics have attempted), he turned to the jurist who understands the meaning of the law from a particular case before him. Although he is concerned with a specific law, its normative meaning is determined in relation to a specific situation in which it is to be applied. "The work of interpretation is to *concretize* the law in each specific case – i.e., it is a work of *application*" (Gadamer, 1960/1994, p.329).

In contrast, a legal historian might seek to understand the meaning of the law by examining the entire range of its applications, mediating disparities between original and current applications of the law. Gadamer wanted to see the historian practice in a manner akin to that of the jurist. Whereas a philologist seeks to understand the meaning of a text in terms of its own truth and beauty, a historian is concerned with something that is not directly expressed in the text itself.

> Thus *for the historian it is a basic principle that tradition is to be interpreted in a sense different from the texts, of themselves, call for.* He will always go back behind them and the meaning they express to inquire into the reality they express involuntarily (Gadamer, 1960/1994, p.336).

Thus, application does not imply the utilization of universal knowledge to a particular case. Rather, the very understanding of the universal itself is affected through the process of understanding the specific case.

Whereas the natural sciences are based on a logic of induction, the human sciences are structured according to the structure of *experience* (*Erfahrung*). Indeed hermeneutics resembles the natural sciences in that methodical experience is required in order to arrive at credible truths; although their epistemological assumptions are highly different. Husserl argued that the natural sciences mistakenly presume a one-sided "idealization of experience." Gadamer and Heidegger in turn criticised Husserl for also being one-sided by his own privileging of perceptual experience, under-recognizing the significance of interpretation.

To conclude this section, the stream of thoughts underlying shifts in conceptions of the human sciences led to the mid-twentieth century currents in hermeneutical philosophy. This outlines the philosophical terrain within which Taylor's ideas emerged. In keeping with Taylor's historically-centered philosophy, understanding Taylor's ideas requires an understanding of the corresponding intellectual context.

The following sections outline the philosophical ideas that Taylor developed within the emerging hermeneutical human sciences and his articulation of his own hermeneutical framework.[13] These include a discussion of Taylor's moral framework and his interpretive "methodology", which serve as the methodological framework for this thesis.

[13] See Smith (2004) for further discussion of how Taylor's thinking is situated within hermeneutical philosophy.

Section II

Understanding Taylor's Human Sciences

In line with Dilthey and Gadamer, Taylor's hermeneutic framework recognizes the primordial importance of *history*. In *Philosophy and its history* (Taylor, 1984), Taylor criticizes the prevalent practices in philosophy as *ahistorical*.[14] For Taylor, philosophical analysis inescapably requires central attention to the historical sources of contemporary phenomena. The past is not simply replaced by the present. Rather, historical roots are necessarily evident in present-day phenomena, although these are commonly unarticulated.

Taylor's historically-grounded hermeneutics builds on Hegel's view of philosophy and history as inseparable. Modern philosophy appeals to an ideal of an atemporal philosophy, according to Taylor, where epistemology presumes to clear away errors or illusions of thought in order to discover greater truths or certainty. Rather, for Taylor, philosophy involves articulating an account of the *origins* of current thoughts, beliefs or practices (Taylor, 1984). These origins are commonly lost through a process of historical forgetting fostered by modern epistemology. Whereas this latter "epistemology model" regards our philosophical awareness of the world as the forming of representations of an "external reality", Taylor argues that philosophy needs to retrieve the (forgotten) foundational formulations of phenomena through an articulation of their historical origins.[15]

[14] Pinkard (2004) has examined the historical orientation of Taylor's philosophy. He highlights what he considers to be apparent gaps in Taylor's thinking, while proposing ways in which these can be reconciled.
[15] James (1994) has challenged some of Taylor's "epochal views" as overly essentialist; that Taylor has not acknowledged that some of these representations are not unanimous. Taylor has responded directly to this criticism in Taylor (1994a).

Taylor has referred to his overall philosophical project as an articulation of a *philosophical anthropology*: the elaboration of an "ontology of man"[16] (Taylor, 1985a). He specified that although hermeneutical inquiry can appear to be an epistemological undertaking – seeking to clarify understanding – epistemological inquiry is inextricable from a corresponding ontological inquiry.[17]

Attempting to clarify the meaning of a thing involves an examination of the nature of the thing itself. Taylor directly challenges "naturalists" – those who adhere to a natural sciences paradigm as the primordial framework for construing all phenomena, including human phenomena (Taylor, 1989).[18] For Taylor, "naturalistic studies of man" *mis*understand human life. Human agency, personhood, or selfhood, central notions in a human sciences framework (i.e., rather than natural sciences), entail a conception of phenomena that is distinctive from mechanistic models of natural phenomena.

Taylor outlines that naturalists regard his hermeneutics as a form of relativism, wherein all truths are arbitrarily created. He also argues that they reject his notion of qualitative distinctions, preferring to place all human goals on the same level, where they are instrumentally judged by the individual in terms of their utility.

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[16] The term "man" is used because it is used throughout Taylor's earlier writings. It is unclear which term would be a suitable non-sexist alternative (e.g., human, person, etc.). No gender discrimination is intended in this discussion.

[17] Dreyfus (2004) has reviewed Taylor's examination of epistemology; referring to Taylor's position as "anti-epistemology". Dreyfus also highlights some concerns regarding Taylor's analysis of epistemology that require further elucidation. For example, Dreyfus asserts that Taylor implies a false inner/outer dichotomy; i.e., between the natural world and the interpreted world. In Dreyfus (2011), he has built on Taylor's hermeneutic account of self-interpreting human practices, by discussing the complex inter-play of natural and human sciences required in medicine.

[18] Geertz (1994) has contested Taylor's characterization of the natural sciences and his distinction of the natural sciences and the human sciences. Geertz, who is renowned for his own promotion of hermeneutics in the human sciences (i.e., primarily in anthropology; Geertz, 1973) has critiqued Taylor's characterization of the natural sciences as (a) "virtually never circumstantial" (i.e., that he inadequately refers to actual examples from the natural sciences) and (b) referring virtually always to the early stages of the scientific revolution and disregarding more contemporary developments in philosophy and science. Taylor has responded directly to this criticism in Taylor (1994a).

Taylor defends his hermeneutical outlook throughout the course of his philosophy, by interpreting naturalism itself as a historically rooted phenomenon, particularly within the human sciences. For example, he has argued that objectivist psychology emerged out of a historical trajectory of positivistic hegemony that subsequently dominated the human sciences, systematically displacing or minimizing subjectivist conceptions of human life (Taylor, 1964).

Behavourism provides a classic example of a naturalistic model of human sciences where learning was construed without regard for associated personal insights, reflections and feelings. This reductive model "side-stepped" consciousness – it was presumed that behaviour could be disengaged from corresponding purpose and intentionality.

Taylor argues that such atomistic accounts misunderstand human agency. Human understanding involves self-understanding – "man is a self-interpreting animal" (Taylor, 1985b). Human agents have understandings and *mis*understandings of themselves – they are also partly constituted by these self-understandings.

> This is a thesis of post-Heideggerian hermeneutics… But it still does not capture the crucial point. This is that our self-understanding essentially incorporates our seeing ourselves against a background of what I have called strong evaluation. I mean by that a background of distinctions between things which are recognized as of categoric or unconditioned or higher importance or worth, and things which lack this are of lesser value… In other terms, to be a full human agent, to be a person or a self in the ordinary meaning, is to exist in a space defined by distinctions of worth. A self is a being for whom certain questions of categoric value have arisen, and received at least partial answers. Perhaps these have been given authoritatively by the culture more than they have been elaborated in the deliberation of the person concerned, but they are his in the sense that they are incorporated into his self-understanding, in some degree and fashion (Taylor 1985a, p.3).

These conditions of worth or value are conveyed by one's culture, incorporated in some ongoing way into one's self-understanding. A naturalistic conception of human sciences cannot adequately grasp human agency.

> For there cannot be no absolute understanding of what we are as persons, and this in two obvious respects. A being who exists only in self-interpretation cannot be understood absolutely; and one who can only be understood against the background of distinctions of worth cannot be captured by a scientific language which essentially aspires to neutrality. Our personhood cannot be treated scientifically in exactly the same way we approach our organic being. What it is to possess a liver or a heart is something I can define quite independently of the space of questions in which I exist for myself, but not what it is to have a self or to be a person (Taylor, 1985a, p.4).

Taylor has argued for an ontological shift in our conception of what we are trying to understand, with a corresponding epistemological shift in how they can be known, following the path built by some of the hermeneutical philosophers discussed above. In contrast to physical, chemical, or biological phenomena that arguably exist in a relatively fixed manner regardless of how we conceive them, understanding human agency inescapably involves interpretation – including self-interpretation. Building on post-Heideggerian hermeneutics, Taylor has asserted that "knowing" human agents are continually understanding through interpretation, while reciprocally being constituted by their self-understandings.

Moreover, humans grasp things in light of background "horizons of significance" – continually discerning phenomena in terms of their broader meaningfulness (Taylor, 1991).[19] How I know or understand something is incontrovertibly rooted in how that thing matters to me, which is in part shaped by the systems of meaning that I am socially embedded within.[20]

[19] Drawing on Gadamer's notion of "horizon" discussed above.
[20] This is developed further below in the discussion of Taylor's *Interpretation and the Sciences of Man* (Taylor, 1985c).

Taylor's Moral Framework

Taylor's examination of the human sciences has focused significantly on moral life and how this can be better understood with the context of modernity. One of the fundamental problems that Taylor believes is faced by the modern world is that many societies, particularly secular ones, cannot appeal to a shared horizon. There does not exist a commonly agreed upon set of goods that appeal to recognized meanings that could help form the basis for community life.[21]

Taylor has outlined that the dominant epistemology of Western modernity, favoring an instrumental proceduralist moral orientation, has suppressed the moral ontology underlying conceptions of human life (Taylor, 1989; 2003). Moral ontology refers to largely implicit background beliefs that persons hold.[22] These are frequently tentative and uncertain, and thus easily suppressed by the dominant moral ideologies. Moral malaises result from the ongoing suppression of this moral ontology (Taylor, 1991). Taylor seeks to render this ontology more explicit through a hermeneutic process of *retrieval*, seeking to articulate these unspoken realms of the moral life (Taylor, 1991).[23]

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[21] This concern is elaborated in section III of this chapter, in the detailed discussion of *Sources of the Self*.
[22] Kerr (2004) has articulated a detailed discussion of Taylor's moral ontology.
[23] Taylor has also examined moral ontology in modernity in light of religious outlooks. In *Varieties of religion today* (Taylor, 2002), Taylor reviews William James' 1902 *The Varieties of Religious Experience* in relation to the prevailing conceptions of religious belief at the time, which Taylor contrasts with contemporary outlooks toward religion, examining the social significance of religion. *A Catholic modernity?* (Taylor, 1999) is Taylor's 1996 Marianist Award Lecture in which he explicitly discussed his own Catholic theological views. He highlights what he considers the failures of religious and secular institutions that have impeded religious belief in current times. His essay is followed by commentaries by William Shea, Rosemary Luling Haughton, George Marsden, and Jean Bethke Elshtain, concluding with Taylor's responses to the commentaries. Additional commentaries have been published regarding Taylor's ideas on religion. For example, Connolly (2004) has argued that although Taylor's examination of Catholicism can enrich philosophical inquiry, his views may conflict with his commitment to the recognition of diversity. Connolly asserts that it appears questionable whether Taylor would recognize non-theistic moral outlooks as comparable to theistically-oriented ones – challenging the depth of Taylor's views on pluralism. Abbey (2004b) responded to this challenge by referring to Taylor's *Varieties of Religion* (Taylor, 2002). Elshtain (2004) has reviewed Taylor's politics of recognition as a framework for rethinking "toleration" in inter-religious discourse.

This moral framework stands in sharp contrast to naturalist conceptions of human agency. The latter regard humans in line with the sciences of nature, favoring a procedural conception of moral life. Discounting the view that moral life is oriented toward ultimate (substantive) goods, proceduralist ethics centers on rational calculative thinking about moral problems. Taylor relates this dominant framework, in part, on the modern Western primacy of instrumental reason, centered on market forces, efficiency, bureaucratic rationality, and entrepreneurial atomism (Taylor, 1991). He criticizes this moral view for its unaddressed questions, such as "Why should one be moral?". Proceduralist ethics cannot adequately address the deeper moral questions underlying ethical concerns, which require an articulation of the ultimate good or right that moral agents seek to orient themselves toward.

The human agent stands against a background "horizon of significance". Although the agent will formulate individual preferences and enact "personal" choices and actions, these cannot be dissociated from the meaningful context within which the agent resides (Taylor, 1989). Human preferences, choices, and actions are rooted in a "moral order" shaped by socio-cultural-historical processes. Societies elaborate their own meaningful order that represents how things matter. Things have meaning and value, which are not arbitrarily or idiosyncratically assigned.

Over the course of time, a society elaborates its own conception of the relative order of various "goods", commonly expressed in terms of beliefs and values. A society's *horizon of significance* serves as its own moral framework for orienting "the good". The elaboration of such a framework involves processes of *qualitative distinctions*, reflectively discerning which actions or modes of life are incomparably higher (Taylor, 1989).

Qualitative distinctions involve a language of "thick description";[24] i.e.,, a language that is culturally attuned and articulates the significance of various views and actions within a culture, in light of local *distinctions of worth* (Taylor, 1985a). Indeed, in his analysis of language, Taylor argues that the hegemonic linguistic conception of language emphasizes the *designative* purpose of language, suppressing the *expressive* purpose of language. Language does not merely point to things. It also articulates the meaningfulness of those things (Taylor, 1985d).[25]

The incomparable higher moral ground implies an alignment with goods or ends that command awe, respect, and admiration. Social communities form converging viewpoints on such goods or ends. [26] Taylor refers to the process of making qualitative distinctions in light of incomparable goods as *strong evaluation* (Taylor, 1989).[27]

Among the incomparable goods, stands the *hypergood*: the incomparably most important standpoint from which all other goods are judged (Taylor, 1989). Various goods have been espoused to be such a *hypergood* in modern philosophy, such as the "categorical imperative" or the "greatest happiness principle". Moral life is challenged when such goods collide or conflict. In such cases, agents may be drawn to an exaggerated reliance on the *hypergood*, disregarding all other goods; or the impossible pursuit of harmony among all goods. In situations where there is a lack of consensus about *hypergoods*, moral skepticism can result.

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[24] The term "thick description" was articulated for anthropology by Geertz in his *The Interpretation of Cultures* (Geertz, 1973) to describe his ethnographic orientation. Geertz adapted the term from philosopher Gilbert Ryle. For Geertz, understanding a phenomenon requires *thick description*, which implies a thorough analysis of the socio-cultural context within which the phenomenon operates.

[25] Taylor's views on "expressivist" and "designative" language are rooted in the ideas of Herder (Taylor, 1985d; 1995b).

[26] Berlin (1994) has argued that Taylor inadequately recognizes that some goods are so diverse that they are irreconcilable. Taylor has responded directly to this criticism in Taylor (1994a).

[27] Weinstock (1994) has articulated a critique of Taylor's notion of *strong evaluation*, while proposing ways in which it can be more favorably argued. Taylor has responded directly to this criticism in Taylor (1994a).

A *hypergood* is a good that supersedes prior *hypergoods* as well as all other contemporary goods. Goods need to be understood in light of transitions, as shifts toward or against a particular *hypergood* are continually ongoing. A *hypergood* is recognized as such when it is regarded as "infinitely valuable" – human agents are moved by it. If one's justification for the current *hypergood* successfully resists error-reducing critiques, then it can be regarded as the *best account*. A best accounted *hypergood* is one that is grounded in the strongest intuitions of a moral community (or society), which successfully meets the challenge of transitions away from that belief.

Agents cannot stand outside of their respective *horizon of significance* and their corresponding moral framework, although these are commonly concealed or suppressed by dominant social ideologies (Taylor, 1989). Retrieving the moral ontology underlying life within particular communities is necessary toward an authentic fulfillment of moral agency. Understanding one's respective *horizon of significance* helps the agent understand where he/she stands in relation to the good.

Moreover, horizons are constitutive of human agency. Human agents are self-interpreting, involving an interpretation of oneself in light of a moral topography: I understand myself in relation to my surrounding systems of worth.[28] Despite modern individualist strivings to be "one's own self", the human agent's identity and corresponding sense of worth is "indissociable" from his/her meaningful horizon (Taylor, 1989).[29]

[28] Descombes (1994) has reviewed Taylor's conception of human agency in sociological "supra-individual" terms, by examining the philosophical tension between individual actions and common actions. Taylor has responded directly to this discussion in Taylor (1994a).

[29] Rorty (1994) and Taylor (1994a) have published exchanges regarding their ontological disagreements, some of which are difficult to discern as they have each articulated these differences somewhat differently. To cite one example, Rorty contests Taylor's views on self-understanding. Taylor responded to this criticism in Taylor (1994a). Skinner (1994) has argued that Taylor's claims appear universalist. Taylor responded in Taylor (1994a).

Interpretation and the Sciences of Man

> Interpretation, in the sense relevant to hermeneutics, is an attempt to make clear, to make sense of an object of study. This object must, therefore, be a text, or a text-analogue, which in some way is confused, incomplete, cloudy, seemingly contradictory – in one way or another unclear. The interpretation aims to bring to light an underlying coherence or sense (Taylor, 1985c, p.15).

Drawing partly on preceding hermeneutical outlooks, Taylor developed his own conception of hermeneutical inquiry, a retrieval framework, which he used to examine the moral problems described above.[30] This framework serves as the methodological orientation of this thesis. Taylor's hermeneutical framework is most explicitly articulated in his paper *Interpretation and the Sciences of Man* (Taylor, 1985c).[31]

Hermeneutical inquiry seeks clarity where meaning appears unclear. Such an analysis involves three conditions. First, an "object or a field of objects" needs to be identified, relating to the thing(s) in which clarity is sought. What thing(s) are we trying to understand?

Second, it is important to distinguish the underlying clarity, sense or coherence that we are seeking from the presenting expression(s) of the former. The meaning underlying a particular text (i.e., the intended message) should not be confused with the text itself (i.e., what was actually written or stated) – the latter is a particular "embodiment" of that meaning. Taylor refers to this as the distinction between meaning and its expression.

Third, the subject for whom the message is meaningful has to be specified. An object or a text does not have meaning in itself – it is meaningful to some subject or a group

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[30] Taylor also examined a large number of questions in political philosophy through his hermeneutical philosophy that are not discussed in this thesis; except for his examination of multiculturalism which is reviewed in Chapter 6 (Taylor, 1992a).

[31] Originally published in: Taylor, C. (1971). Interpretation and the Sciences of Man. *The Review of Metaphysics*, 25(1), 3-51.

of subjects. The interpretation of religious texts does not imply the discerning of an absolute ultimate sense. Rather, this involves a clarification how this is meaningful to a particular person or group of persons.

Understanding through interpretation involves a "hermeneutical circle" – an analysis of "part-whole" relations, attempting to understand the sense underlying the whole through a serial reading of parts. Our analysis of an object (e.g., a text) is always provisional and prone to interpretive disagreements, where others may not infer the same sense from the object.

> What we are trying to establish is a common reading of text or expressions, and what we appeal to as our grounds for this reading can only be other readings. The circle can also be put in terms of part-whole relations: we are trying to establish a reading for the whole text, and for this we appeal to readings of its partial expressions; and yet because we are dealing with meaning, with making sense, where expressions only make sense or not in relation to others, the readings of partial expressions depend on those of others, and ultimately of the whole (Taylor, 1985c, p.36).

Interpretation involves a fundamental tension regarding *certainty*. There have been two dominant epistemological traditions toward the pursuit of truth: the "rationalist" pursuit of absolute inner clarity of mind (e.g., Hegel) and the "empiricist" striving to go beyond subjectivity that turns to brute data as building blocks for understanding (e.g., Locke), leading to the ideal of verification advanced by the logical empiricists. Taylor links the certainty-pursuits of contemporary epistemology and the "study of man" to the rise of computer-oriented theories of human thinking and a prevailing natural sciences framework for the human sciences. The triumphs of the natural sciences have profoundly captured the imagination of modern western thought and how things ought to be understood, adopted by many as the best or only paradigm for the human sciences.

For Taylor, uncertainty is an ineradicable part of our epistemological predicament (Taylor, 1985c). A better understanding of human phenomena can only imply a clearer grasp of the object – understanding cannot be certain. Human expression (i.e., written, spoken, action) conveys meaning – meaning that can only be understood through interpretation. Thus, Taylor argues that the human sciences are inescapably hermeneutical.

Meaning here does not refer to the linguistic sense where language is examined in terms of how things are designated (Taylor, 1985d). For example, a linguistic meaning of the term "photograph" can be made to be quite "exact" so that there can be agreement about the attributes required for a thing to qualify as a photograph. However, a photograph can have a hermeneutic sense as a meaningful expression, such as commemoration of a deceased loved one or a striving to make permanent a highly cherished yet episodic moment in life.

Hermeneutic meaning is always for a subject or group of subjects – it does not exist in a detached objective vacuum. As stated earlier, meaning relates to an object, such as a text. For example, a United Nations Declaration is an object that can express meaning – the object and its meaning(s) are different things.

Moreover,

> [T]hings only have meaning in a field, that is, in relation to the meanings of other things. This means that there is no such thing as a single, unrelated meaningful element; and it means that changes in the other meanings in the field can involve changes in the given element. Meanings cannot be identified except in relation to others, and in this may resemble words. The meaning of a word depends, for instance, on those words with which it contrasts, on those that define its place in language…, on those that define the activity or "language game" it figures in, and so on (Taylor, 1985c, p. 22).

Things are understood in relation to other similar or contrasting things – they stand in relation to one another.

An interpretation can be strengthened through further analyses of other available expressions of the object in question. For example, an analysis of the United Nations *Convention on the Rights of the Child* can result in a variety of interpretations (UN Convention, 1989). The meaning of the text can be further clarified by examining other texts that articulate the aims of the *Convention*. However, such analyses will not necessarily discern a single ultimate meaning, because the meaning that will be drawn will relate to the subject for whom the text is meaningful – which can vary from one subject to another.[32]

Moreover, the possibility of converging understandings of the same text among subjects requires a shared understanding of the language involved. For example, if one subject holds a universal view of rights that transcends place and time and another has a relativistic view of rights, that the significance of rights are relative to contextual considerations such as culture, they will likely arrive at quite distinctive interpretations of the UN Convention. However, they can be challenged to discern the originally intended meaning of the *Convention* by examining additional expressions (e.g., supporting documents).

To consider a clinical problem, in examining the moral permissibility of withdrawing medically administered nutrition from a neurologically impaired child, one can turn to the leading statements of North American ethical and legal pediatric norms published by the American Academy of Pediatrics (1994; 1995) and the Canadian Pediatric Society (2004). These clearly centre on the *best interests* standard. These sources argue that tube-feeding is a medical treatment and should therefore be examined in light of how it serves the child's *best interests*, by weighing the benefits and burdens associated with the

[32] The United Nations *Convention on the Rights of the Child* is examined in detail later in the thesis (UN Convention, 1989) – particularly in chapter 4.

"treatment", such as the preservation of life and the relief of hunger and thirst versus the prolongation of suffering. However, in the actual practice of feeding cessation, families and clinicians report a variety of discomforts (Diekema & Botkin, 2009). These can be minimized as mere emotional distress related to the grave condition of the child, or, these can be manifestations of moral distress – an expression of moral residue due to the moral problems that remain unarticulated with a simple benefits/burdens calculus of the child's best interests as outlined in the texts above. Perhaps, the texts do not go far enough in articulating the range of morally meaningful considerations for such situations. Moral agents may bring a diverse set of moral views regarding nutrition and the feeding of sick children, drawn from their respective *horizons of significance*. Consequently, understanding the meaning of *best interests* involves a significant order of complexity that can be readily misunderstood without a rigorous hermeneutical method.

Hermeneutic meaning refers to the experiential significance of a thing for a subject. An action relates to a purpose with corresponding "desires, feelings, emotions." Understanding is in turn hermeneutically circular. The term "shame" cannot be understood without examining *situations* that can be shameful or humiliating, which also relates to other contrasting notions such as pride and honor.

> Ultimately, a good explanation is one which makes sense of the behavior; but then to appreciate a good explanation, one has to agree on what makes good sense; what makes good sense is a function of one's readings; and these in turn are based on the kind of sense one understands (Taylor, 1985c, p. 24).

Hermeneutic interpretation involves a circular form of reading, continually striving toward greater clarity of the implied meaning, while continually questioning what constitutes "greater clarity of the implied meaning".

Taylor argues elsewhere that man is a "self-interpreting animal" (Taylor, 1985b).

> [W]hat is interpreted is itself an interpretation: a self-interpretation which is embedded in a stream of action. It is an interpretation of experiential meaning which contributes to the constitution of this meaning. Or to put it in another way, that of which we are trying to find the coherence is itself partly constituted by self-interpretation (Taylor, 1985c, p. 26).

That which humans interpret is interpreted in a stream of other interpretations – which ultimately involve a process of self-constitution. We come to understand ourselves through our processes of interpretations – self-interpretations performed in a social context that appeal to networks of intersubjective interpretations. Persons construct meanings in relation with other persons – intersubjectively. Intersubjective meanings form the basis for our self-understandings, while they are also constitutive of our social realities. Intersubjective meanings form the basis of shared values and understandings that enable the possibility of a common world among some groups, typically regarded as communities[33]. Ultimately, all such meanings and understandings are historically rooted – continually colored by how things have come to be regarded in a particular manner.

For what concerns human beings, understanding involves subjective personal engagement in a meaningful realm, rather than objective detached examination. Our interpretations are in part constituted by our self-understandings – while the latter are also in part constituted by the former. Taylor's notion of *social imaginaries* – described below - articulates a framework for understanding the meaningful field within which things are interpreted; the background for the *horizons of significance* against which things have meaning.

The preceding discussion outlines Taylor's conception of hermeneutical inquiry and his argument that human sciences are inescapably hermeneutical. Taylor's hermeneutical "methodology" can be further understood by reviewing his own philosophical

[33] This point is further developed in *Modern Social Imaginaries* (Taylor, 2004).

investigations as illustrative demonstrations. Taylor's analyses of personal identity in modernity (Taylor 1989; 1991) and secularization (Taylor, 2007; 2011a) provide strong demonstrations of his hermeneutical framework.[34] Section III of this chapter examines some of this work, advancing an explicitation of the *horizons of significance* and *social imaginaries* underlying the analysis of modern pediatric medicine that follows in subsequent chapters.[35]

Understanding Moral Life in Light of *Social Imaginaries*

A prominent feature of Taylor's hermeneutic framework is his focus on socio-cultural-historical context. Drawing on his argument that things have meaning in relation to other meanings, these need to be understood in relation to prior (i.e., historical) and surrounding (i.e., socio-cultural) systems of meaning that in part shape the meaning of the object of interest.

This socio-cultural-historical focus is further developed in his concept of *Social Imaginaries* (SI), which provides a conceptual "toile de fond" for understanding moral frameworks, norms, and practices in light of corresponding societal processes (Taylor, 2004). Consistent with his hermeneutical philosophy, SI are identified and analyzed through an examination of historical and socio-cultural sources relevant for the question at hand.

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[34] Some of Taylor's discussions of secularization have included exchanges with Habermas. In his essay "Why we need a radical redefinition of secularism", Taylor (2011b) examines the place of religion in secularist states, critiquing in part Habermas' distinction between "secular reason" and "religious thought" wherein Habermas favors the former. This debate is further developed in the published dialogue following Taylor's paper (Habermas & Taylor, 2011). Additional exchanges between Taylor and Habermas have been published regarding their respective "moral philosophy"; published by themselves and various commentators. For example, see DeSouza (1998) for a discussion of Taylor's critiques of Habermas' theory of discourse ethics or discourse theory of morality; which is accompanied by Taylor's reply (Taylor, 1998a).

[35] *Social imaginaries* are discussed in the next section.

SI are shared by a large group, referring to a group of people's common understanding of their social surroundings, and the group's common practices and shared legitimacy. SI are more than social norms or ideological doctrine. Rather, they refer to how a group of people (or a society) understands itself as well as its practices. According to Taylor, hermeneutical analysis has to grasp the *Social Imaginary* or *imaginaries* corresponding with the object being examined.[36]

The emergence of modern moral orders.

Taylor's SI is adapted from Benedict Anderson's acclaimed Imagined Communities (1983) wherein Anderson argues for a definition of a nation as "an imagined political community."

> It is *imagined* because the members of even the smallest nation will never know most of their fellow-members, meet them, or even hear of them, yet in the minds of each lives the image of their communion (Anderson, 1983, p. 6).

Taylor develops his notion of SI in the context of his analysis of Western modernity. He argues that there are in fact multiple modernities, each involving an amalgam of new practices, institutional forms, new ways of living, and new forms of malaise.[37] SI shape the moral order of a society, which is characterized by the *economy*, the *public sphere*, and a *self-governing people*.

[36] For a critical discussion of Taylor's *Modern Social Imaginaries* - examining problems relating to "multiple modernities", the relation of SI with ethical and political deliberation, and how to specify or discern a social imaginary - see the Disputatio collection of papers in *Philosophiques* Volume 33, number 2, published in 2006. These include Précis de *Modern Social Imaginaries* by Taylor (2006a); Imaginaires sociaux et modernités multiples by McCarthy (2006); De l'herméneutique de la modernité à l'éthique normative : commentaire sur *Modern Social Imaginaries* by Maclure (2006); and L'identité des imaginaires sociaux et la nature des droits by Patton (2006); followed by Taylor's replies in Taylor (2006b).

[37] This conception of "multiple modernities" is helpful, later in the thesis, toward understanding contemporary pediatric medicine against a backdrop of multiple and diverse historical, social, and moral sources. These sources are impacting current understandings of the moral dimension of childhood, although these understandings may be largely concealed; which can be better understood through the hermeneutical retrieval articulated in the following chapters.

According to Taylor, modern moral orders have been shaped by 17th century theories of natural law. Grotius' natural law regarded the normative order as a derivation of its constituting members, who were rational, sociable, and mutually benefiting agents. Society was regarded as an ensemble of "individuals" wherein they individually consented to the legitimization of a particular political authority. This view of moral order was further advanced by Locke's defense of individual rights. Consequently, over the next three centuries, society was seen as existing for the mutual benefit of its members.

This Grotian-Locke moral order displaced longstanding pre-modern hierarchical views that corresponded with hierarchies in the cosmos. This involved a hierarchical complementarity – the distribution of functions partially defined the normative order. In contrast, with modern moral orders, individuals serve each other's needs as rational social creatures whose functions are all changeable whenever judged necessary. The purpose of an organization is to serve the instrumental ends of its free agents, who provide service to each other, in order to ensure collective security and economic prosperity. Whereas in Plato's *Republic*, hierarchical order is in itself a moral end wherein mutual service is a virtue.

Taylor argues that we become embedded in modern categories such that our societal views are distorted. As moderns, we conclude that we are essentially individuals and that the displacement of prior communal hierarchies has liberated us from constraining old moral orders. Over time, we have come to believe that we are more individualistic and less communal – because individualism is in our nature. Taylor cautions against this distorted

view of history. We have always lived in forms of communities. We need to better understand how these communities shape their corresponding moral orders.[38]

Social Imaginaries defined.

Taylor defines a *Social Imaginary* as

> the ways people imagine their social existence, how they fit together with others, how things go on between them and their fellows, the expectations that are normally met, and the deeper normative notions and images that underlie these expectations (Taylor, 2004, p.23).

Taylor contrasts *Social Imaginary* and Social Theory.[39] A Social Theory is commonly possessed by only a few (usually elite) members of a society. In contrast, a *Social Imaginary* is shared by a large group, referring to a group of people's common understanding of their social surroundings, and the group's common practices and shared legitimacy. However, Social Theory and *Social Imaginary* can also be related. The Social Theory held by an elite few can gradually infiltrate a *Social Imaginary* and become more and more shared. A *Social Imaginary* is more than social norms or ideological doctrine. Rather, it refers to how a group of people (or a society) understands itself as well as its practices.[40]

[38] This conception of the "social construction of moral orders" informs the detailed analysis of shifting conceptions of childhood and children as moral entities, in the following chapters.
[39] This distinction helps differentiate Taylor's socio-historically-rooted hermeneutics from social theoretical approaches as frameworks for examining social structures, processes, and systems.
[40] Hulak (2010) has examined Taylor's SI in relation to a wittgensteinian approach to the analysis of constitutive social rules, arguing that SI may advance our understanding of cultural and political identity but not the historical constitution of social practices.

The Great Disembedding.

Taylor traces the emergence of modern SI to a profound disembedding of individuals.[41] Premodern individuals were embedded in three ways: (1) Socially – whereby religious life was linked with social life, involving a "higher" relation with the spiritual; (2) Religious Action – whereby society related to God as a community comprised of a social matrix that defined personal identity, sacrosanct roles (e.g., priest, shaman, or chief) and collective action (i.e., one could not have imagined oneself outside of such a matrix); and (3) Human Flourishing is related to a higher good, rather than an end in itself.

Modernity gave rise to a disembedding of these forms whereby society becomes a willed cooperation among free individuals.[42] Individuals now have a new (free) relationship with the divine and flourishing is no longer linked to the sacred. Taylor emphasizes that modern individualism should not be regarded a *subtraction* story (i.e., the erosion of prior social horizons), but rather as the emergence of a new self-understanding in society – a new relationship with each other. We shift from one *Social Imaginary* to another.

Three forms of social self-understanding.

A central argument put forth by Taylor is that there are three forms of social self-understanding that are central to modernity, as stated above: (1) the economy; (2) the public sphere; and (3) a self-governing people.

[41] Taylor's notion of "disembedding" helps account for the processes involved in shifts in SI. This illuminates the shifting understandings of childhood and corresponding moral outlooks discussed in the following chapters.

[42] Some aspects of modernity resulting from this disembedding are further discussed in section III, which help account for the moral outlooks that have come to characterize modernity.

The economy.

As modern societies considered that human life was designed for the purposes of mutual benefit, the expedient realization of such benefits acquired a central importance. Social relations involved a meshwork of interrelated purposes that should be efficiently designed. Drawing on Locke's natural law theory where the goals of organized society are the ensuring of security and economic prosperity, economics (i.e., exchange of services) became regarded as a fundamental end (not means) of society. Society *should* be ordered and productive. This corresponded with the post-Reformation sanctification of ordinary life, whereby the common pursuit of family prosperity became the highest form of Christian life.[43]

The public sphere.

The public sphere refers to a common space where members of a society meet through a variety of media to discuss matters of common interest and form a common mind. The public sphere transcends topical space, including larger spaces of non-assembly, partly constituted by common understandings. Public opinion assumes a normative importance that the government should listen to, because this public is a sovereign people. Public discourse in modernity is based on human reason, not the will of God, power of nature, or traditional authority. Thus, the public is now construed in highly secular terms.

A self-governing people.

Taylor discusses how a theory of popular sovereignty can infiltrate a *Social Imaginary*. The theory can inspire new practices and then shape the *Social Imaginary* of those who adapt

[43] The foundational importance of the economy in shaping social self-understandings is apparent in chapter 3, which highlights how economic considerations affected moral-value conceptions of children over time.

these practices. Or, the *Social Imaginary* can change through a reinterpretation of prior practices, with a corresponding transformation of forms of legitimacy.

Taylor examines the emergence of popular sovereignty through a comparative analysis of the American and French Revolutions. The idea of popular sovereignty that emerged in the American Revolution was continuous with a preceding British and American order of natural law which gave importance to elected assemblies and consent to taxation. The new constitution regarded the will of the people as the source of law through a retrospective reinterpretation of prior law. There was no radical break with prior meanings.

Taylor contrasts this with the French Revolution, where there was a shift of legitimacy from dynastic rule to a sovereign nation. Although self-rule through elected assembly was already practiced in Anglo-Saxon societies, there was little understanding of representative constitution in France. There were no shared meanings in the pre and post French Revolution SI. This shift was strongly influenced by particular features of French thought, especially the ideas of Rousseau. Rousseau asserted the idea of "la volonté générale", arguing that life plans within a society should harmonize, balancing the love of self with a desire to fulfill the wishes of others. Political representation is seen as a transparent openly created general will that fuses individual and common wills.

Although both Revolutions gave rise to sovereign self-ruling societies, this involved different kinds of shifts in SI, appealing to different conceptions of a self-governing people.

Contemporary *Social Imaginaries*.

Taylor outlines some additional transitions, following the 18th century SI outlined above, that contributed to the contemporary Imaginaries that are now commonplace in the West.

These initial changes in the moral order in the economic, public sphere, and self-rule dimensions of social life were not immediately extended into other realms. For example, for some time, the family remained a social system of dependencies with an uncontested patriarchy – a hierarchical complementarity of superior-subordinate relationships contributing to each other's well-being. The subsequent collapse of these hierarchies led to the disintegration of corresponding ties, resulting in a significant atomization.

Gradually, the new moral order infiltrated all niches of social life to shape the new *Social Imaginary*. This new *Imaginary* is centered on a conception of individualism that shifts one's tie to society. An ideal of personal independence now regards self-reliance as a virtue.[44] Taylor emphasizes that the new *Social Imaginary* does not displace the old, but rather reinterprets central values of the prior *Imaginary*. He argues that societies find ways to retain a sense of continuity with their origins as their *Imaginaries* shift.[45]

General comments on *Social Imaginaries*.

Taylor's SI enrich the hermeneutical framework for this thesis, toward examining the moral malaises of modern pediatric medicine. SI provide an innovative framework for understanding moral orders within particular societies, and the historical influences that have shaped them. SI are particularly interesting because they imply a much broader and more pertinent framework than social theory or ideology. Furthermore, Taylor exhibits his usual historical hermeneutic methodology to demonstrate how SI take shape.

[44] This corresponds with contemporary moral outlooks that appear to be centered on personal and family autonomy, which have shaped current ethical views within pediatric medicine; as discussed in subsequent chapters.

[45] This inter-relation among prior and new SI is demonstrated in the following chapters, as early moral conceptions of children persist – sometimes implicitly – despite the emergence of newer conceptions. This helps advance our understanding of the multiplicity of moral outlooks underlying contemporary pediatric medicine.

Taylor has not explicitly discussed how his more recently articulated notion of SI is related to *horizons of significance*. For the purposes of this investigation, I have inferred from Taylor's writings that *horizons of significance* develop within SI. That is, SI exist at a broad social level, within which social groups, subgroups and/or communities form their respective *horizons of significance*. In short, I consider *horizons of significance* as a "subset" of SI. A SI can be characterized as morally pluralistic, as a multiplicity of socio-moral communities can develop within a social space or a society, each drawing on their respective *horizons of significance*. This pluralism can also be traced to ongoing shifts among earlier and newer *horizons of significance*, giving rise to ongoing shifts in SI. In contrast, SI can be characterized as significantly "homogenous" and stable, with relatively limited diversity and temporal shifting in *horizons of significance*. This latter characterization seems to correspond with historically earlier epochs of more limited cross-societal intersections.

Section III

The Moral Malaises of Modernity

In this section, I outline some substantive aspects of Taylor's hermeneutical analyses that are relevant for the investigation undertaken in this thesis. These build on Taylor's moral framework, which was reviewed in the previous section.

Specifically, I outline the moral malaises that characterize modernity, according to Taylor. This discussion highlights the moral frameworks that are dominant in contemporary Western societies, illuminating the "moral horizon" against which modern medicine, bioethics, and pediatric ethics have emerged. This discussion serves as an intellectual "mise

en scène" for the hermeneutical analysis of pediatric medicine that will follow. This will inform the articulations of the *horizons of significance* and SI underlying modern pediatric medicine, which are developed throughout the following chapters.

In *The Malaise of Modernity*, Taylor argued that the modern self struggles with three principal malaises (Taylor, 1991). First, the rise of individualism has been celebrated for giving human agents the freedom to choose by breaking loose from older moral horizons. But these moral horizons gave meaning to the world and social life. The fading of these moral horizons has resulted in the loss of a meaningful order and a loss of meaning for the self. This is discussed further below in the section on modern individualism and the inward self.

Second, instrumental reason has been assigned a fundamental importance. Although this can be considered both liberating and empowering for individual agents, it has given rise to a worldview where maximizing efficiency has become a primordial good. Humans, and other creatures, lose their significance as they become regarded as materials (i.e., instruments). Human life has become a means rather than an end. The modern self is entrapped in a Weber's "iron cage" of technology. This is discussed in greater detail in the section on the affirmation of ordinary life.

Finally, the first two malaises give rise to consequences for political life. Humans have become construed as atomistic means where they come to feel as powerless (i.e., meaningless) individuals. This third malaise is revisited in chapter 5 in a discussion of political agency in pediatric medicine.

Sources of the Self is Taylor's philosophical treatise that examines the sources of these malaises (Taylor, 1989). Consistent with his conception of hermeneutics, Taylor's

analysis of modernity draws on his re-interpretation of the historical origins of the modern self.[46]

Modernity has constructed for itself a narrative of progress, characterized by liberation, triumph, and evolution. Liberation from the obligation to conform to religiously prescribed norms, triumphant progress out of the pre-scientific "ignorance" and bestiality of the "Dark Age", and an overall evolution of the "fittest" species in the universe.

Taylor's analysis has demonstrated that this contemporary worldview is not a *necessary* course for human thought. Indeed not all cultures of the World have embraced the Western conception of the self.[47]

The Western *individualistic instrumental atomistic* self has been construed to conform to a new (i.e., modern) "cosmic order". In pre-modernity, the order of the universe was teleologically theistic, drawing heavily on the influences of Augustine and Aquinas. All phenomena were believed to be oriented toward divinely defined ends. The human pursuit of knowledge was supposed to seek an understanding of this order and its underlying divinity.

The scientific revolution displaced this pre-existing meaningful order to one of simple instrumental means toward humanly-chosen ends. Once science was able to disprove such divine notions as geocentrism (i.e., the earth as the center of the universe – displaced by Copernicus), the Ancient Greek idea of perfection of the "heavens" (i.e., "disproved" by Galileo), the genesis of living species (i.e., overthrown by Darwin),

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[46] Elshtain (1994) has argued that Taylor's account of modernity is too optimistic, inadequately recognizing some problems as irreconcilable. Taylor has responded directly to this criticism in Taylor (1994a).

[47] This "cultural" argument regarding conceptions of the self is not significantly developed by Taylor in *Sources of the Self*. On the other hand, cross-cultural examinations of the self have been examined quite extensively in anthropological and related literature, which corroborate Taylor's argument. For examples, see: Anscombe (1989); Carrithers, Collins, & Lukes (1985); Geertz (1983); Kirmayer (1989); Kleinman (1988); Markus & Kitayama (1991); Shweder & Bourne (1982); Spiro (1993).

Christian accounts of the universe lost their grip. The universe was now a reality of mechanical objects whose properties could (and should) be revealed through systematic observation and manipulation.

Taylor demonstrates that although this creates a possibility for extraordinary human empowerment – that humans could grasp and control phenomena that were previously within the exclusive domain of God – a corresponding order that can attribute a higher purpose or significance to human life is displaced; resulting in a vacuous moral order.[48]

Critics of the modern Western self simply attack the rise of modernity and its corresponding scientific revolution and secularization as the "causes" of the malaises of the modern self. They put forth a narrative of decline. This sentimental longing for a pre-scientific self has historically forgotten the Platonic-Augustine influences on the course of the self. The latter cultivated the conditions for recognizing the "self dimension" of human agency. Humans were not simply mindless beasts that required disciplining in order to conform to a broader order, as is often conveyed by accounts of the modernization of the self.

The *inward turn* started with Plato and was further developed by Augustine as an ontological framework for their epistemological questions. The human pursuit of truth or knowledge could not be detached from the human's foundational place in the universe – as

[48] The term "vacuous" is used here to refer to Taylor's characterization of modernity's account of an apparent negation, displacement, or erasure of a substantive moral ground. The moral ground of modernity is to appear "vacuous" as prior teleologically-oriented groundings are contested and rejected – as described throughout Taylor's examination of modernity and secularization. The espoused moral outlooks of modernity are to be considered "freed" of any such moral content. However, throughout his hermeneutical philosophy and his analyses of modernity, Taylor argues that prior moral grounds cannot be erased; rather, they are concealed. These can be "unconcealed" through hermeneutical retrieval, as discussed earlier in this chapter. Therefore, the term "vacuous" in this thesis implies "apparently, espoused, or allegedly vacuous", according to modernist claims. The phrase "vacuous moral order" in this sentence should be read as "apparently, espoused, or allegedly vacuous moral order". The term "vacuous" is used throughout this thesis, as a "shorthand" representation of "apparently, espoused, or allegedly vacuous".

a being within a meaningful cosmic order. Discovering truths was necessarily tied to better understanding one's place in the universe and with God. The notions of self-mastery and inwardness were developed as means to an ultimate end: understanding the theistic teleological cosmic order.

Modernity's displacement of teleological cosmic orders gave rise to an intellectual context where the inner self remained the "site" for the processes of inquiry, but the substance of this inner inquiry was evacuated of its prior contents. Descartes, Locke, and Montaigne particularly rendered the self as its own ultimate arbiter for ascertaining truths and the truths that were worth investigating.

Modernity gave rise to an epistemology centered on the disengaged self (i.e., disconnected from any wider meaningful moral order) – as an end rather than a means - without explicitly examining the corresponding ontological implications. The modern self finds itself in the pursuit of truths without any underlying framework for assigning meaning to such pursuits, other than the "affirmation of ordinary life" through the instrumental control of the universe for the independently chosen wishes of the individual.

Thus, Taylor's hermeneutical analysis of the modern Western self has unconcealed numerous important features of this phenomenon. First, the malaises of the modern self are not a necessary consequence of the scientific revolution and secularization. These latter events have enabled the human control and alleviation of a great deal of human suffering; for example, through the advancement of scientific medicine, which has supplanted the prior turning to religion for the cure of medical problems.

Second, Western societies have discovered other ways of organizing themselves to pursue the good of humanity as well as spirituality, which is not constrained by the frequently hegemonic institutions of religion. There does exist a potential for "good

liberation" of human life through the displacement of religious structures. These possibilities are attributable to modernity's further articulation of the inner self, which originated with Plato and Augustine.

However, Taylor has also highlighted that modernity's crisis of meaning can be attributed to its dominant *ontology-less* epistemology: the pursuit of truths without an explicitly recognized and commonly shared overarching meaning or purpose. The wholesale rejection of cosmic orders has also obscured primordial moral sources for human life – the ultimate goods toward which one's life can be oriented. Taylor calls for societal contemplation of this predicament and large-scale engagement in the resolution of this "angst".

This understanding of the modern Western self has been made possible through Taylor's historically-centered hermeneutics. That is, his understanding of this phenomenon necessitated an interpretation (indeed a re-interpretation) of its sources. Although modernity's origins are typically traced to the rise of 16^{th}-17^{th} century shifts of thought, Taylor's hermeneutics called for a re-reading of this era, by examining the course of some central notions leading up to the modern era, such as knowledge and self.

This re-reading of past texts has enlightened our understanding of a current-day question, in keeping with the tenets of Taylor's hermeneutical framework. In contrast to a simplistic (i.e., incomplete) condemnation of the modern self as excessively egocentric or a celebration of its self-empowering liberation, Taylor has enabled us to grasp this phenomenon in a more meaningful manner. We have a fuller account of how the modern

self has come have its current features, with its corresponding pleasures and malaises, and where we ought to turn to seek a reconciliation of the problems that have emerged.[49]

In the following sections, I examine two phenomena highlighted by Taylor in his analysis of moral agency in modernity: (1) the rise of inward individualism and (2) the affirmation of ordinary life. The former will help outline the moral horizon against which the dominant contemporary bioethical principle of autonomy has emerged, while the latter illuminates the instrumental conception of the good life underlying the calculus of benefits and burdens commonly used to determine a person's *best interests*.[50]

The Emergence of Modern Individualism - *Sources* of the Inward Self

Taylor highlights that the modern notion of selfhood is unquestioningly framed within an underlying conception of inner/outer. Thoughts and feelings are seen to reside on the inside of the self, while the objects that mental events relate to are on the outside. He argues that this has been become fixed onto a particularly modern self-understanding that is historically rooted.

In keeping with Taylor's hermeneutics, understanding this inward self in modernity, necessarily calls for a philosophical analysis of its historical origins.[51,52]

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[49] Taylor can be criticized for not going far enough in articulating how the malaises of modernity could be reconciled.

[50] These links to contemporary bioethics are developed in subsequent chapters of the thesis.

[51] Ricoeur (1998) has critically reviewed Taylor's historical analytical framework in *Sources of the Self*. Ricoeur examines a deep "epistemological" tension between anthropologically foundational and historical analytical orientations in analyzing the shaping of moral outlooks. Taylor responds to these critiques in "Le fondamental dans l'histoire" (Taylor, 1998b). For a comparative examination of the work of Taylor and Ricoeur on the self, see Dauenhauer's (1992) essay, contrasting Taylor's (1989) *Sources of the Self* with Ricoeur's (1990) *Soi-même comme un autre*.

[52] This discussion of Taylor's analysis of the "sources of the modern inward self" is presented in a sketch-like format, in the interests of succinctness. This highlights major epochal transformations in conceptions of selfhood - along with corresponding implications for "the good life" – as well as the leading thinkers that Taylor associates with these changing conceptions. Given the complex demonstrations of these historical periods presented by Taylor in *Sources of the Self*, I recognize that this overview risks an appearance of over-

Taylor regards Augustine as an early "source" of the modern self. Given that Augustine drew so heavily from Plato, the latter's influence also merits attention.

Plato's *Republic* put forth a notion of self-mastery. He regarded reason as a higher moral source - higher than desire - that leads to a self-mastery; consisting of unity with oneself, calmness, and a collected self-possession. Reason is regarded as a capacity to recognize an underlying order, which can be discerned by correct "vision". In the allegory of the Cave, reason guides our understanding from illusion to wisdom.

The contemplation of an unchanging order (i.e., *theōria*) is a higher activity that brings you closer to the divine. The mind is conveyed as a unitary space, which implies an interior dimension; although Plato did not explicitly use an inner/outer metaphor. It is important to note that Plato's self-mastery has no individualistic tone. Rather, it involves the individual's striving to be attuned to the universe and the divine – to the whole; the Ideas.

Taylor credits Augustine as the first thinker to introduce the inner/outer distinction in the Western conception of self. Augustine's doctrine outlines two principal loves: love of the "outer" referring to the bodily, sensing, beastly realm, and love of the "inner" which relates to a radical reflexive inward road to God.

> Augustine's proof of God is a proof from the first-person experience of knowing and reasoning. I am aware of my own sensing and thinking; and in reflecting on this, I am made aware of its dependence on something beyond it, something common. But this turns out on further examination to include not just objects to be known but also the very standards which reason gives allegiance to. So I recognize that this activity which is mine is grounded on and presupposes something higher

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simplification. This brief discussion is intended to convey the extraordinary shifts in outlooks – later characterized by Taylor as SI – in conceptions of the self leading into the modern era. This also sheds light on the series of earlier outlooks that have been concealed in modernity, toward which contemporary hermeneutical analyses should be oriented. Taylor's historical hermeneutical examination of the self, as well as other phenomena highlighted in this chapter, helped orient my investigation of modern pediatric medicine as I sought to identify earlier historical outlooks and examine how these have been retained, transformed, or concealed over time. This investigation is presented in the following chapters.

> than I, something which I should look up to and revere. By going inward, I am drawn upward (Taylor, 1989, p.132).

This first-person experience of knowing and reasoning involves a pursuit of self-certainty, congruent with Plato's self-mastery, that strives toward oneness with the cosmic order and the divine. Augustine's first-person experience of knowing and reasoning served as an important inspiration to Descartes, who took reason into a significantly new direction.

Descartes accepted Augustine's radical reflexivity and the view that the proof of God's existence lies within our own ideas. However, Descartes construed inwardness in a new light – in keeping with the changing worldviews of the 17th century. This was an epoch where a teleological cosmic order was rejected, the universe became mechanistic, and representational scientific knowledge came to be regarded as "true" knowledge.

The self was no longer to seek attunement to outside moral sources because the presumed moral goodness of the universe collapsed. Rather, the pursuit of truth or knowledge required external observation – the need to step outside of the self and its distorting subjectivist tendencies. The ideal road to knowledge required a disengaged stance from the body (i.e., disembodiment). In the newly "discovered" reality without an underlying "good" cosmic order, reason now involved a capacity to construct order that met the contemporary standards of certainty. The cosmos was demystified as a moral end to seek attunement with, to a merely mechanistic means toward rational mastery through instrumental control.

Moral sources no longer resided in the external order, but within the agent's own sense of human dignity. Inner rational strength – and a corresponding capacity to master the universe – now became a virtue in itself; not as a means to a higher good. Rationality is no longer defined substantively, aligned with an underlying order. It is now construed

procedurally in terms of rigorous thinking. Whereas Augustine's inward turn was an upward turn, Descartes' inwardness was a move toward certainty.

Descartes' disengaged disembodied construal of human knowledge was radically transformed through what Taylor refers to as Locke's "punctual self". Locke argued for a categorically anti-teleological view of human nature. There were no innate human ideas. Rather, all ideas were formed through sensation and reflection. All ideas could be traced to simple ideas acquired through sense experience, which then serve as building blocks for complex ideas.

Locke put forth a tremendously individualistic atomistic mind – an extraordinary departure from Plato's self-mastery. This move was congruent with the contemporary mechanization of the universe. Ideas were now construed as building blocks that could be arranged in a multitude of ways, without constraint from any supposed underlying cosmic order.

Taylor argues that Locke's punctual self was reinforced by the Protestant principle of personal adhesion, wherein pleasure was regarded as good and pain as evil and humans should be impelled toward a self-making that brings about the best results or happiness. This set an important groundwork for the elaboration of utilitarianism; and its powerful influence on Western moral theory.

Taylor highlights a concurrent - possibly countercurrent - conception of the self that was affirmed in the late 16th century by Montaigne. Whereas Descartes implied a universal human nature that could be understood by following universal criteria and a disengagement from ordinary experience, Montaigne rejected the possibility of a universal human nature, arguing that perpetual change was everywhere. This Renaissance scholar asserted that self-knowledge should be pursued, rather than universal knowledge. Each person should search

for his/her own original identity, seeking and accepting what he/she essentially is. This was part of a Renaissance 17th century shift that saw a rise in the writings of ordinary English men and women, also consistent with the Protestant ideal of introspection.

By the 18th century, the conception of the present day self becomes recognizable. The self is regarded as original, individually committed, and independent. This independence is viewed as self-responsible and endowed with individual rights. Humans are seen as political atoms. A reductionistic conception of society and community prevails, that is reducible to the desires and actions of individuals. The purposes of human action are not seen as part of a cosmic order but rather as highly individual, to be discovered "within" in light of each person's own motivations.

The Affirmation of Ordinary Life

Taylor has argued that Western modernity has centered "goodness" in ordinary living, production, reproduction, and the family; displacing the previously espoused higher activities of the "good life" (i.e., contemplation and the citizen life) (Taylor, 1989). The latter were regarded as inegalitarian, because only an elite minority was deemed capable of fulfilling them. Leading an ordinary life, with a maximization of prosperity and relief of suffering for all, was seen as a new way to the good life that was open to all. This shift was strongly advocated by the Reformers, "The really holy life for the Christian was within ordinary life itself, living in work and household in a Christian and worshipful manner" (Taylor, 1996, p.4).

A similar critique was then launched by secularists against the Christian Reformers.

> Christianity, according to the secularists, allegedly scorns the real, sensual, earthly human good for some purely imaginary higher end, the pursuit of which can only lead to the frustration of the real good and to suffering and repression. The

> motivations of those who espouse this "higher" path are thus suspect (Taylor, 1996, p.4).

Thus Western modernity has undergone two major shifts in moral orientation: (1) a move from the good life aligned with the "higher" forms of holiness espoused by Catholicism and its hierarchy of access to goodness, to a Reformed holy life actualized through "inward" family-centered worship and everyday work; followed by (2) the rise of secularism and a more complete "inward turn" away from a Christian moral life and its corresponding goods, toward individually chosen goods (i.e., moral ends), and instrumentally efficacious means to fulfill them.

The latter is congruent with Francis Bacon's call on science "for the relief of man's estate".[53] However, Taylor points out that this often turned out to exclusively serve the ends of greater control and technological mastery, concealing the complex moral ground that had given meaning to such human pursuits. Taylor highlights that these shifts, since the eighteenth century, have given rise to a sense of disenchantment and loss. For example, the Romanticists rebelled against the growing instrumentalization of life, without regard for the fuller moral realms of life.

A Final Remark on Taylor's Modern Self

> A fully competent human agent not only has some understanding (which may be also more or less *mis*understanding) of himself, but is partly constituted by this understanding… [O]ur self-understanding essentially incorporates our seeing ourselves against a background of what I have called 'strong evaluation'. I mean by that a background of distinctions between things which are recognized as of categoric or unconditioned or higher importance or worth… In other terms, to be a full human agent, to be a person or a self in the ordinary meaning, is to exist in a space defined by distinctions of worth (Taylor, 1985a, p.3).

[53] Specifically, in his 1605 *The Advancement of Learning,* Francis Bacon asserted "Science discovery should be driven not just by the quest for intellectual enlightenment, but also for the relief of man's estate".

Charles Taylor has articulated not only a methodological framework for philosophical analysis, but also a conception of human understanding: an ontologically-grounded epistemology. Humans understand things in terms of how things matter for them. This implies a process of interpretation against the interpretive horizon within which the agent resides. The human agent continually craves a meaningful understanding.

Similarly, philosophical analysis involves, for Taylor, a process of interpretation against the interpretive horizon within which the current intellectual tradition resides. He has re-interpreted the contemporary angst and malaises of modernity in terms of a historical hermeneutics that traces the sources of the modern Western self, to articulate an account that "un-forgets" the origins of the inward self - how this was not inherently inclined toward an *individualistic instrumental atomism*. An inward self is not necessarily destined to the collapse of a meaningful order and the malaises that consequently ensue.

Understanding human phenomena, like the modern self, requires an interpretation of their historical origins and the horizons of meaning they emerged from. Taylor's *Sources of the Self* (1989) offers an exemplar of this philosophical "methodology". Taylor has demonstrated the rich moral sources of modern phenomena that can be unconcealed through his hermeneutical framework. This helps justify the selection of Taylor's philosophy for the analysis of pediatric medicine in this thesis.

Having discussed Taylor's philosophical conception of the human sciences, his corresponding moral framework and his notion of SI, as well as his analysis of selected concerns in modernity, a Taylorian hermeneutical methodology for this thesis is outlined in the next chapter; grounded in Taylor's philosophical ideas examined in this chapter.

Chapter 2: Designing a "Taylorian" Examination of the Moral Malaises of Modern Pediatric Medicine

Taylor's hermeneutics provides a rich philosophical framework for examining moral matters. However, Taylor does not provide specific detail on how to conduct his methodological approach. How does one perform a Taylorian hermeneutic analysis of the moral malaises of modern pediatric medicine?

In this chapter, I articulate a methodology that "operationalizes" Taylor's *hermeneutical retrieval*, which is used for the philosophical examination of the moral malaises of modern pediatric medicine in subsequent chapters. This requires an elucidation of the SI surrounding contemporary conceptions of pediatric medicine, as well as corresponding *horizons of significance* relating to the moral life of children. This methodological adaptation of Taylor's work, for this thesis, presents an important contribution in itself.

This design is inspired both by (a) Taylor's philosophical articulations (i.e., his discussion of a hermeneutic framework for philosophy as well as his philosophical analyses of modernity and moral life, described in the preceding chapter), which demonstrate his "practice" of hermeneutics and outline a number of concepts central to his moral framework; and (b) Benner's (1994a) development of a "Taylorian" methodology for phenomenological empirical research in the health sciences.[1] The latter extends the former in explicating specific analytical "techniques" for examining texts and other expressions such as interviews and observations. However, this thesis remains a philosophical

[1] In *Interpretive phenomenology: Embodiment, caring, and ethics in health and illness*, Benner (1994a) has edited a collection of papers that articulates a hermeneutical framework for conducting empirical qualitative research, drawing heavily on the ideas of Taylor as well as Heidegger. This collections also provides several examples of completed research that used this methodological orientation.

investigation – Benner's methods were used solely to orient the identification, analysis and interpretation of the texts examined in the thesis.

Analytical Sources

In keeping with the hermeneutical tradition, texts were the foundational sources for this investigation, serving as articulations of particular SI and *horizons of significance* within which various conceptions of childhood, medicine, and the good were identified. It is a premise of this investigation that shifts in moral outlooks in general and moral conceptions regarding childhood in particular, leading to the current modern Western notion of child's *best interests*, can be identified and examined through traces recorded in various forms of texts (e.g., medical or social sciences publications, state reports, legislation). Some examples are listed below.

Hermeneutic analysis of texts unfolds over a prolonged period of time whereby provisional interpretations can be articulated through essays, publications, seminars, or conference papers. Corresponding peer critique assists in the ongoing review and re-interpretation of texts as the interpretivist re-articulates his/her unfolding analysis in subsequent papers. Toward this end, I engaged in a large number of formal and informal scholarly activities over the years that this investigation was conducted. These enabled me to advance the numerous analyses that informed the investigation.[2]

Ongoing critique and advisory processes were incorporated into the analysis of texts. A group of experts with expertise in domains related to this investigation served as consultants throughout the course of this analysis.[3] Consultations with experts informed the

[2] Some of these have been published independently and are cited in this thesis.
[3] This consultation process is described below.

ongoing process of identifying seminal texts, prioritizing these texts, and reviewing the various streams of interpretations that could be drawn from them.

The preliminary analysis discussed below outlines a collection of texts and experts that served as a "starting point" for this investigation.[4] *Experts* were identified through an analysis of major publications, through which principal authors were identified, along with supplemental authors cited in each paper's references. In turn, consultations with recognized experts in pediatric ethics pointed to relevant *texts* (e.g., articles, books, legal documents, reports) examining moral concerns relating to children.

Additional sources were sought through a "snowball effect" - texts and experts led to further sources through the guiding questions outlined below, leading to a progressive expansion of the depth and scope of sources informing this investigation. This "sampling" process continued until the investigation achieved "analytical coherence and density". That is, the analysis was continued until a coherent "best account" of the moral malaises of modern pediatric medicine could be articulated, that reconciled emerging counterviews and contradictions, with highly "dense" or "thick" supporting argumentation and sources.[5] This "analytical coherence and density" was corroborated through discussions with the expert consultants and the thesis supervisor.

[4] This so-called starting point is hardly the beginning of this investigation, as several years of inquiry informed the preparation of this proposed "starting point".
[5] The term "thick" is used here in line with Geertz's notion of "thick description" described in chapter 2 (Geertz, 1973).

Analytical Plan

Empirical studies are commonly oriented by interview or observation guides[6], which enable the researcher to formulate the detailed aims of the study, clarifying the significance of material as central, secondary, or irrelevant, and specifying required analytical strategies. A provisional *Investigation Guide* was developed to help orient the inquiry (see below). This provided a series of "guiding questions" that were continually used for the investigation of texts and consultations with experts, to discern what was meaningful in relation to the aims of the analysis. The guide was adapted over the course of the investigation as new questions, speculations, and "findings" were formulated. This adaptation was undertaken in continual consultation with the expert consultants, to help guard against "confirmatory bias" – that is, the investigator's inadvertent imposition of an *a priori* interpretive bias. The entire analysis was conducted with the ongoing guidance and supervision of the thesis supervisor.

All materials were examined through a series of part-whole analyses. Each source was first reviewed in its entirety, to derive the overall intended coherence. In turn, parts of the whole were examined directly, continually seeking to enrich my understanding of the questions outlined in the *Investigation Guide*. These "parts analyses" were then related back to my initial interpretation of the whole to see if it could be better understood in light of its parts.

The overarching aim of this investigation was to articulate the SI and related *horizons of significance* within which the objects of the analysis dwell, and the *hypergoods* that could dominate corresponding conceptions of the good in relation to childhood. As

[6] Such empirical guides may be fixed for the entire duration of a study, or fluidly adapted in relation to emerging findings, depending on the aims of the study (Benner, 1994a).

demonstrated by Taylor, things are morally meaningful in relation to a socio-cultural-historical context. A Taylorian hermeneutical examination of "the child" as a moral entity and corresponding entities (e.g., parents, family, medicine) required an articulation of how meaningfulness was constituted in a specific time and place.

Some sample analyses are briefly described, which guided the early design and initiation of this investigation by: (1) illustrating how existing texts could serve as rich sources toward fulfilling the aims of this thesis and (2) demonstrating some "fragments" of prior analyses relevant to advancing our understanding of moral conceptions of children. The latter served as secondary sources for this investigation, but in many cases the primary sources used in these analyses were re-examined in light of the aims of this investigation. Primary and secondary sources helped sketch the SI within which children have been construed both inside and outside of medicine. Moreover, these sources were examined with a Taylorian hermeneutic framework to retrieve the *horizons of significance*, SI, goods, and *hypergoods* corresponding with moral conceptions of children.

For example, some historians and sociologists, through their analyses of a wide range of texts, demonstrated that the construction of "childhood" is a relatively recent phenomenon.[7] The demarcation of "childhood" as a distinction from "adulthood" in Western societies can be traced to the seventeenth century. Ariés (Ariés, 1960/1962) found that prior to this era children were construed as mini-adults. Here we can identify the early emergence of the potential for children as "socially meaningful" entities within the SI of the time. But the moral significance attributed to children at the time and how this unfolded over time remained unarticulated.

[7] Ariés (1960/1962), James, Jenks, & Prout (1998), and Prout (2000), among others, provide comprehensive examinations of the socio-historical construction of childhood. This body of work is discussed in detail in the following three chapters.

The medical recognition of infant mortality as a medical problem that medicine should prevent has been traced to a quite recent time – the early 1900s. Through his historigraphical examination of British medical and social texts, Wright (1988) highlighted that prior to this time infant mortality was regarded as a "normal" occurrence. Families typically conceived a large number of children, some of whom would survive and some would die. However, turn-of-the-century shifts in urbanization and industrialization resulted in fertility decreases. As family size decreased, each individual child assumed a greater "value" both in terms of family life for the production of future family laborers and the transmission of family heritage and wealth as well as for the overall societal labor force and economy. We can see here a recognition of the child as a good – a valuable family and social resource, threatened by high rates of infant mortality. It then became a scientific and moral priority for medicine to prevent infant deaths. The turn to medicine, rather than the Church for example, demonstrates how medicine was emerging as a prime institution in secularizing Britain at the time, vested with the societal mandate for "managing" death. We can thus see the emergence of death-prevention and medicine as goods within the SI and *horizons of significance* of the time and place – within which the preservation of the life of a child emerged as a primary good.

In a recent examination of contemporary medical paternalism in French pediatric medicine, Carnevale and Bibeau (2007) investigated the roots of the powerfully autonomous decisional status accorded to pediatricians in France. It seemed noteworthy that physician authority supersedes that of parents. An investigation of various state documents and scholarly works highlighted that physician authority appears rooted in an underlying state paternalism towards the care of children in France. Whereas Anglo-Saxon societies are centered on an "individualistic Protestant ethic", France (and possibly other

Latin European countries) appear to have retained a "collectivist ethic" wherein the state regulates parental authority in most realms of children's lives, such as schooling and medicine. The moral authority exerted by the state in France was recently demonstrated in the debate regarding the wearing of religious symbols (e.g., Muslim veils) in public institutions. The French government-commissioned Stasi Report (2003) analyzed this issue in light of so-called fundamental values of "La République". This Report outlines a vision of the French nation as a society with a fixed identity wherein "the foreign" are required to "integrate". In the name of social cohesion, (religious) preferences of individual citizens are subordinated to those of the state's determination of what is best for its people as individuals and as a collective. This state paternalism expresses the French notion of "la nation" as a commitment to "vouloir vivre en commun". This has been affirmed through the IIIe République française, adopted in the early 1870s. This body of national legislation outlined public powers in a manner that explicitly established the French state's protective powers towards "its" children. This enabled subsequent national programs for obligatory vaccination or child confiscation, as deemed necessary by the state. The state exercises its authority over children, in part, through its physicians. Within the French SI, state regulation of all aspects of the lives of children, including schooling and medicine, in line with the state's aims of preserving a collectivistic ethic can be regarded as a form of *hypergood* – a good which supersedes the recognition of parents as decisional agents for children.

In short, this preliminary analysis helped demonstrate that a Taylorian hermeneutical analysis of "the child" as a moral entity within corresponding SI, through an examination of selected texts, could help retrieve the *horizons of significance*, SI, goods

and ultimate *hypergoods* corresponding with moral conceptions of children in Western medicine and enrich our understanding of the moral malaises of pediatric medicine.

Analytical Guide

A preliminary analysis was conducted to identify (a) specific "guiding questions" that should be formulated as initial operational tools to pursue the aims of this investigation (outlined below) and (b) textual sources that should be examined to retrieve the SI and *horizons of significance* underlying the moral malaises of modern pediatric medicine (described in the *Provisional Sources* section below).

This section describes how the analysis of texts was oriented, in light of the guiding questions outlined below. All materials examined for this study, texts and comments from experts, were identified and selected in relation to their relevance to the moral malaises of modern pediatric medicine. Specifically, this relevance was defined in terms of their relation to ethical or moral considerations regarding children's encounters with health, illness, and medical care, elucidating background conceptions of the child as a moral entity. For the purposes of this investigation, the child was regarded as a moral entity that can be construed as a moral *object* toward whom others have interests and obligations and/or a moral *subject* with a subjective moral life, moral agency capacities, and potential or actual responsibilities toward others.

Texts were continually examined in light of the provisional questions outlined below. The development of these questions entailed a preliminary hermeneutical elucidation of the substantive ground of this examination; i.e., how can we better understand the moral malaises of modern pediatric medicine? These questions, as well as

the textual and expert sources that the questions were directed toward, were adapted over time as described above.

Guiding questions.

Two categories of questions oriented this investigation: (1) *Text identification questions* and (2) *Text analysis questions*.

Text identification questions.

These questions aimed to explicitly articulate how the search for texts should be designed, how texts should be sampled and which texts should be included or excluded.

- Which sources (e.g., electronic databases, digital or material libraries) should be searched to identify texts relating to the moral malaises of modern pediatric medicine?
- Which *specific* texts address questions or problems that relate to the moral malaises of modern pediatric medicine?
- What type of search should be used for each category of text? (e.g., narrative, scoping, systematic)
- Which inclusion/exclusion criteria should be used to identify these texts?
- Which search strategies should be used? (e.g., specific key words and search structure designs)

Text analysis questions.

These questions aimed to explicitly articulate how the texts should be examined to elucidate the moral malaises of modern pediatric medicine.

- What does this mean?
- What deeper meaning(s) underlies this assertion?
- What is the source of this deeper meaning?
- Which background *social imaginary* and/or *horizon of significance* is this meaning rooted in?
- What conceptions of right/wrong, good/bad, just/unjust underlie this assertion?
- Which meaning(s) are concealed?
- Which conceptions of right/wrong, good/bad, just/unjust are concealed?

Provisional Sources

A broad and thick body of documents have been published addressing a wide variety of topics relevant to the moral malaise of modern pediatric medicine. Drawing on the *Text Identification Questions* outlined above, a search of these materials was conducted to determine (a) which could be relevant for this investigation and (b) how these could be adequately categorized. This process was highly inclusive to guard against the risk of discarding materials that could be relevant even if not readily apparent.

The materials examined at the onset of this investigation are listed below. These were identified primarily through publication databases and reference lists in "seminal" works as well as consultations with a variety of scholars (described below). As described above, this was a provisional list that was adapted over the course of the investigation.

To ensure a rich perspective on advancing our understanding of the SI and *horizons of significance* underlying the moral malaises of modern pediatric medicine, an interdisciplinary body of materials was sought. Virtually all scholarly disciplines – including the clinical sciences, social sciences, and the humanities - that have published materials relating to the child as a moral object or subject were included; specifically: anthropology of childhood; child law; history of childhood; pediatric bioethics; pediatric clinical sciences (e.g., child psychology, pediatric medicine, pediatric nursing); philosophy of childhood; and sociology of childhood.

Many of the texts listed below were not retained in the end for the investigation because they were not relevant for the primary focus of this analysis, while some additional texts were identified and added. All texts that were retained in the analysis are cited in the following chapters and listed in the references at the end of the thesis.

Anthropology of childhood: anthropological analyses of the child as a moral object/subject in society in general and in medicine in specific

Bluebond-Langner, Myra. 1978. *The Private Worlds of Dying Children*.

Sheper-Hughes, Nancy & Sargent, Carolyn. 1998. *Private Wars: The cultural politics of childhood.*

Child law: legal tetxts and analyses of the child as a moral object/subject in society in general and in medicine in specific

UN Convention on the Rights of the Child

Quebec Civil Code

Canadian/American laws, doctrine and jurisprudence relating to children requiring medical care

Quebec Youth Protection Act

Canadian/American laws, doctrine and jurisprudence relating to youth protection

Koocher, G.P. and Keith-Spiegel, P.C. 1990. *Children, ethics, and the law: Professional issues and cases*.

Ridgway, Derry. 2004. *Court-Mediated Disputes Between Physicians and Families Over the Medical Care of Children*.

History of childhood: historiographic analyses of the child as a moral object/subject in society in general and in medicine in specific

Ariés, Philippe. 1960/1962. *Centuries of Childhood: A social history of family life*.

Carol, Anne. 2004. *Les médecins et la mort: XIXe – XXe siècle*.

Comacchio, C., Golden, J. & Weisz, G. 2008. *Healing the World's Children: Interdisciplinary Perspectives on Child Health in the Twentieth Century.*

DeMause, L. 1976. *The History of Childhood*.

Durand, Duplantie, Laroche, Laudy. 2000. *Histoire de l'éthique médicale et infirmière*.

Walwin, J. 1982. *A Child's World: A social history of childhood 1800-1914*.

Wright, Peter. 1988. *Babyhood: The social construction of infant care as a medical problem in England in the years around 1900*.

Pediatric bioethics: bioethical analyses of the child as a moral object/subject in society in general and in medicine in specific

Baylis, F., Downie, J. and Kenny, M. 1999. *Children and decision making in health research*.

Blustein, J. 1993. *The family in medical decision-making.*

Buchanan, A.E. and Brock, D.W. 1990. *Deciding for others: The ethics of surrogate decision making*.

Gaylin & Macklin. 1982. *Who Speaks for the Child? The problems of proxy consent*.

Harrison, C., Kenny, N.P., Sidarous, M., and Rowell, M. 1997. *Bioethics for clinicians: Involving children in medical decisions.*

Jonsen, Al. 1998. *The Birth of Bioethics*.

Kopelman, L.M. 1995. Children: Health-care and research issues. In W.T. Reich (Ed.), *Encyclopedia of bioethics* (pp. 357–367).

Lantos, John. 2001. *The Lazarus Case: Life-and-death issues in neonatal intensive care*.
Lantos, John & Meadows, William. 2006. *Neonatal Bioethics: The moral challenges of medical innovation*.
Medical Research Council of Canada, Natural Sciences and Engineering Research Council of Canada, and Social Sciences and Humanities Research Council of Canada. 1998. *Tri-Council Policy Statement: Ethical Conduct for Research Involving Humans*. Ottawa: Public Works and Government Services Canada.
Murray & Caplan. 1985. *Which Babies Shall Live? Humanistic dimensions of the care of imperiled newborns.*
Nelson, H.L. and Nelson, J.L. 1995. *The patient in the family: An ethics of medicine and families*.
Ross, Lainie. 1998. *Children, Families, and Health Care Decision-Making*.
Ross, Lainie. 2003. *Responding to the Challenge of the Children's Health Act: An Introduction to Children in Research.*

Pediatric clinical sciences (including child psychology, pediatric medicine, pediatric nursing): clinical analyses of the child as a moral object/subject in society in general and in medicine in specific

American Academy of Pediatrics. 1994. *Guidelines on forgoing life-sustaining medical treatment*.
American Academy of Pediatrics. 1995. *Informed consent, parental permission, and assent in pediatric practice*.
Bearison, D.J. 2006. *When treatment fails: How medicine cares for dying children*.
Canadian Pediatric Society. 2004. *Treatment decisions regarding infants, children and adolescents*.
Sourkes, Barbara. 1995. *Armfuls of Time: The psychological experience of the child with a life-threatening illness.*

Philosophy of childhood: philosophical analyses of the child as a moral object/subject in society in general and in medicine in specific

Archard, David. 1993. *Children: Rights and Childhood*.
Archard, David & Macleod, Colin. 2002. *The Moral and Political Status of Children*.
Attig, T. 1996. Beyond pain: The existential suffering of children.
Coles, R. 1986. *The moral life of children*.
Erikson, E.H. 1950. *Childhood and society*.
Kagan J. and Lamb S. 1987. *The Emergence of Morality in Young Children*.
Matthews, Gareth. 1996. *The Philosophy of Childhood*.
McCormick, Richard & Ramsey, Paul. 1974-1976. *Series of papers between Richard McCormick and Paul Ramsey debating the ethics of experimenting with children.*
Miller, Richard. 2003. *Children, Ethics & Modern Medicine*.
Piaget, J. 1932/1965. *The moral judgment of the child*.

Sociology of childhood: sociological analyses of the child as a moral object/subject in society in general and in medicine in specific

Various authors in the Journal *Childhood*.
De Singly, Francois. 2004. *Enfants Adultes: Vers un egalite de status?*
Heimer, Carol & Staffen, Lisa. 1998. *For the Sake of the Children: The social organization of responsibility I the hospital and the home*.
James, Allison; Jenks, Chris; Prout, Alan. 1998. *Theorizing Childhood*.
Mayall, Berry. 2002. *Towards a Sociology for Childhood: Thinking from children's lives*.
Mayall, Berry. 1996. *Children, Health and the Social Order*.
Prout, Alan. 2000. *The Body, Childhood and Society*.
Qvortrup, Jens. 2005. *Studies in Modern Childhood*.
Stephens, S. 1995. *Children and the politics of culture*.

Consultations with Scholarly Experts

As described above, various scholars were consulted throughout this investigation in order to (a) further refine the identification of relevant texts and (b) review the interpretations generated through the course of this investigation. As mentioned earlier in this chapter, these consultations were oriented by the *Guiding Questions* for this investigation. All of the consultations were conducted in person, with some follow-up exchanges by email.

The consultants helped elucidate background meanings that could underlie the texts, from different disciplinary interpretive frames. Most of the following scholars were consulted before the investigation was fully initiated, to help guide the initial analyses.

This following list outlines some of the principle experts that were consulted, to illustrate the depth and scope of this investigation. Many additional experts were consulted, who are not included in this list.

Anthropologists of childhood

Gilles Bibeau (Université de Montréal)
Sylvie Fortin (Université de Montréal)
Myra Bluebond-Langner (Rutgers University-Camden, USA)

Bioethicists of childhood

Kathleen Glass (McGill University)
Chris Feudtner (University of Pennsylvania,USA)
Lainie Ross (University of Chicago, USA)

Clinical scholars of childhood

Chris Feudtner (University of Pennsylvania,USA)
Lainie Ross (University of Chicago, USA)
Nico Trocmé (McGill University)
Delphine Collin-Vézina (McGill University)

Historians of childhood

George Weisz (McGill University)
Catherine Rollet (Université de Versailles, France)

Legal scholars of childhood

Angela Campbell (McGill University)
Shauna Van Praugh (McGill University)

Philosophers of childhood

David Archard (Lancaster University, UK)
Daniel Weinstock (Université de Montréal)

Sociologists of childhood

Patricia McKeever (University of Toronto)
Alan Prout (Warwick University, UK)

Description of Analytical Chapters that Follow

In the following two chapters, I present initial hermeneutical analyses of the sources described above; respectively, an examination of (a) the early history of pediatric medicine (chapter 3) and (b) the *best interests* of the child (chapter 4). These are followed in chapter 5 by a substantive re-examination of these analyses in light of Taylor's moral framework and his analysis of modernity.

Chapter 3: Early History of Pediatric Medicine

Introduction

In keeping with Taylor's conception of hermeneutical analysis, historical texts were examined to identify the *social imaginaries* (SI) and *horizons of significance* underlying contemporary pediatric medicine and its corresponding moral frameworks. A librarian, Mr. Chris Lyons, at the McGill University Osler Library of History of Medicine and a medical historian, Professor George Weisz at McGill University,[1] were consulted for guidance on how to identify valid historical sources.[2] Given the vast scope of this historical inquiry, it was concluded that secondary texts would be the best historical sources. Secondary texts are analyses or syntheses of original texts published in the past.

Three key textbooks were identified to provide the historical foundation for this analysis: (1) *History of medicine: a scandalously short introduction* by Jacalyn Duffin (1999); (2) *The greatest benefit to mankind: a medical history of humanity* by Roy Porter (1997); and (3) *The Cambridge world history of medical ethics* edited by Robert Baker and Laurence McCullough (2009). Additional texts (i.e., primary and secondary sources) were also consulted, to further examine emerging themes.

References are cited heavily throughout this chapter to indicate the specific sources of the historical "findings" relevant to the social construction of childhood indentified in this analysis.

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[1] Professor Weisz also has expertise in the historical examination of childhood health; e.g., he is co-editor of *Healing the World's Children: Interdisciplinary Perspectives on Child Health in the Twentieth Century* (Comacchio, Golden, & Weisz, 2008).

[2] Additional experts were consulted for this and subsequent chapters, as described in the previous chapter.

This analysis focused primarily on the North American context, however some European texts were also consulted to further examine particular themes where European practices appeared to have an important influence in North America. The analysis in this chapter covers historical contexts up to the 1970s, before the *Presidents Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research* (1983), which marked a normative turning point and the "birth of bioethics" in North America.[3]

The examination of these texts was oriented by the guiding questions outlined in chapter 2. The principal themes that were identified are discussed as they emerged through historical periods, leading to the current era. This analysis focused primarily on the domain of health. Future analyses of other childhood domains, such as education, would further enrich our understanding of children as moral entities.[4]

The historical analyses discussed in this chapter differ somewhat from the analyses in subsequent chapters. Whereas the latter directly examine a number of moral and ethical aspects relating to children, this chapter presents little *explicit* moral/ethical content. This historical overview highlights the early "emergence" of childhood as a new social category – as a form of ontological shift. Yet, this shift also involved largely-implicit morally-meaningful considerations. Although childhood norms are difficult to discern in this early period, it is still possible to identify the corresponding moral signification attributed to children (e.g., they were largely regarded as instrumental means toward the interest ends of adults and state bodies). This analysis is incontrovertible toward elucidating the SI and

[3] For a detailed discussion of the "origins" of bioethics in North America, see Jonsen (1998).
[4] Toward that end, in part, a broader socio-historical examination of childhood is discussed in the following two chapters.

horizons of significance leading to contemporary conceptions of children in modern pediatric medicine.

The "Origin" of Childhood

French historian Philippe Ariès (1960/1962), historian of childhood and author of *Centuries of Childhood*, is recognized for identifying a key historical transition in the construal of childhood. Through his analysis of depictions of children in art, Ariès demonstrated that before the 17th century, children were predominantly regarded as small adults. The Renaissance marked the beginning construal of childhood as a distinctive life phase, and children as fundamentally different from adults. This transition is referred to by some as the "social construction of childhood" – children and childhood became recognized as distinctive because of changing ideas. This early process of distinguishing children from adults appears to have marked an ontological shift. That is, persons in the early years of life became gradually recognized as a distinctive type of person. The ontologically distinguishing aspects of children[5] and the corresponding moral implications[6] took a diversity of forms over time. The features of these shifts are discussed further in chapter 5.

The recognition of childhood as a socially constructed category provided an analytical backdrop for this investigation. Given that childhood has been socially constructed, this investigation sought to explicitate the moral considerations underlying these social construction processes.

[5] That is, in what ways were children to be defined or differentiated from adults?
[6] For example, and following from Taylor's moral philosophical framework, what moral ontology characterized this emergent ontological entity called childhood?

Childhood as a State Interest

> Childhood is the most intensively governed sector of personal existence. In different ways, at different times, and by many different routes varying from one section of society to another, the health, welfare, and rearing of children has been linked in thought and practice to the destiny of the nation and the responsibilities of the state. The modern child has become the focus of innumerable projects that purport to safeguard it from physical, sexual and moral danger, to ensure its normal development, to actively promote certain capacities of attributes such as intelligence, educability and emotional stability (Rose, 1989, p.121).

The twentieth century Fordist[7] conception of children drew on the seventeenth to nineteenth century rise of military and economic competition through colonization. During this time, childhood was increasingly seen as a site of investment for the future – for both families and the state. This "evolved" from the 17th century European relationship between rulers and ruled that was based on a "gamekeeper" metaphor. State ruling was like maintaining a population of animals on a territory: shaping the land, extracting the maximum benefit, and eliminating "weeds".

Education emerged as a means of eliminating "ignorance" among the "peasants". Education was a state disciplining force used to "cultivate" the strength of the state. In this light, children were seen as sites of investment for the future of the state, justifying their isolation from mainstream society (e.g., in schools) to promote their optimal cultivation – in line with a view of children as dependent (Bauman, 1987). Education was also directed to wealthy mothers to "improve" their child-rearing practices in order to optimize their children's development into stable and independent adults (Donzelot, 1979).

This state-governance of childhood operated as the socio-political context within which medicine became involved in the lives of children, as described below.

[7] "Fordism" as an economic and social phenomenon is discussed in detail in chapter 5.

Discovery of Infant Mortality

The moral worthiness of the lives of individual children has not consistently held a universal value. Wright's (1988) historical analysis of the medicalization of infant mortality in turn-of-the-century England (from 19th to 20th century) highlighted that the turn to medicine to combat the high prevalence of infant death corresponded with a period of urbanization and diminution of family size; increasing each child's worth as a future source of labour and revenue. Infant survival was not initially regarded as a worthy end in itself, but as a means to promoting state economic and military ends.

As the decreasing number of children became a concern, infant mortality was examined and the very high rates caused a shocking revelation in 18th century Europe and North America.[8]

Particularly striking were the very high mortality rates that were measured in foundling hospitals, regarded as a horrifying surprise (Duffin, 1999). Foundling hospitals were created for abandoned newborns; developed initially in 13th century Italy and then in other European countries. Baker and McCullough (2009) have argued that foundling homes merely served as a socially acceptable facade for infanticide – to dispose of socially undesirable infants.

The control of infant death became regarded as a marker of progress; infant mortality became an index of population health (Porter, 1997), as well as a matter of national pride. Child care was considered an indicator of human civilization (Duffin, 1999). Thus, the diminution of infant mortality became a medical imperative.

[8] For a detailed discussion, see Duffin (1999). For a specific review in the French context, see the work of French demographer Catherine Rollet (Gourdon & Rollet, 2009; Rollet, 1999; 2000) and French sociologist Anne Paillet (Paillet, 2007).

Medicalization of Birth and Child Care

A major response to rising concern about infant mortality was the "medicalization" of childbirth, starting in the 18th century, developing more fully in the 20th century. As late as 1900, in Europe and North America, less than 5 percent of births occurred in hospitals (Baker & McCullough, 2009). By the end of the 20th century, more than 95% of births in Europe and North America were in hospitals.

This process of medicalization had several features. This included a shift in the locus of responsibility for children from the personal domain of woman and home to the professional domain of (male) physicians and the hospital (Baker & McCullough, 2009). Prior to medicalization, childbirth was an exclusively female social event. Throughout most of Western history, male professionals did not attend births until the 17th and 18th centuries (Duffin, 1999).

Women's social soles were significantly centered on motherhood, breastfeeding, and baby welfare (Porter, 1997). Children were regarded as the property of their fathers, yet responsibility for their care resided with women (i.e., mothers and nurses); not (male) doctors (Duffin, 1999). Social hygiene views of the time blamed mothers and nurses for the suffering and loss of children. Although physicians gave some pediatric advice from at least the 17th century, this had little overall impact; children remained the "business" of mothers and nurses (Porter, 1997). Early developments in anaesthesia for mothers were met with remarkable resistance. Christian ideology held that women were meant to suffer in childbirth (Bible - Genesis 3:16 in Duffin, 1999, p.256).

Eventually, the entry of men into the care of childbirth was justified by the promise that medical men could offer women less painful, but more importantly, safer deliveries of healthier children (Baker & McCullough, 2009). In an attempt to eliminate midwives, the

medical profession did not encourage the development of midwifery skills, despite the fact that the United States had some of highest maternal death rates in the developed world (Porter, 1997).

Medicalization of infant and child well-being was state-mediated. The fate of innocent children became a matter of national pride (Duffin, 1999). Many Western states started to take a greater interest in the health and welfare of children. However, state interest in infant survival can be traced to ancient times. Caesarean birth originated in antiquity, for cases where the mother was dying or dead. Roman law authorized caesarean births to save the infant for the state.

Specifically, the medicalization of infant and child well-being was mediated by state investment in motherhood and infant welfare (Porter, 1997). Parents were instructed on how their children should be raised. Monetary reward programs were developed for the number of children in families; i.e., active pro-natalist policies (Duffin, 1999). The social hygiene movement became connected to the aspirations of developed nations. Children were regarded as the future; their welfare reflected that of the state.

However, over time, questions emerged: Should all lives be saved? Should all citizens become parents (Duffin, 1999)? For example, Haeckel argued that for the physically and mentally “handicapped” child, morphine or cyanide would “free this pitiable creature” itself but also its relatives (Haeckel cited in Weikart, 2004, p.147). In 1870s Britain, some advocated abandoning and directly killing infants with "incurable conditions" (Pernick, 1996). In 1917 America, the film “The Black Stork” was released as a “eugenic love story'” (Pernick, 1996). Eugenicist/surgeon Harry J. Haiselden warned “ill-matched” couples against marriage because they would produce “defective offspring”. Haiselden

refused to perform needed surgery for children with selected birth defects and allowed them to die, as an act of eugenics.

A eugenics movement emerged in the early 20th century, where nature was seen as more important than nurture; breeding stock mattered more than environmental variables. Eugenists advocated stricter marriage regulation, tax reform to encourage the middle classes to produce more babies, detaining defectives, and (voluntary or compulsory) sterilization of the unfit (Porter, 1997).

In time, medicalization moved beyond childbirth and into the general domain of child health and welfare. Early medical care of children resisted any recognition that children required different therapies, applying adult treatments to children, often with disastrous consequences for children (Pawluch, 1983).

Medicine gradually fixed its gaze on “sickly infants”, “backward children”, as well as inherited conditions, among others (Porter, 1997). Attention was directed to congenital tendencies to sickness surfacing among populations rendered dysfunctional and unproductive by poverty, ignorance, inequality, poor diet and housing, unemployment, or overwork.

Children's hospitals were set up in Paris in 1802, Berlin in 1830, St. Petersburg in 1834, and Vienna in 1837. Subsequently, the United States looked to Britain for models of child medical care (Porter, 1997).

The Birth of Pediatrics

Pediatrics, from the Greek words for “child” and “healer”, came into being in the late 19th century (Duffin, 1999), emerging as a medical specialty. The word "pediatrics" first appeared in print in 1884; "pediatrician," someone who specializes in treating

childhood diseases, first appeared in print in 1903 (Baker & McCullough, 2009). This corresponded with a critical period in medicine, as science was slowly accepted as the new paradigm for the profession.[9]

Pediatrics was seen as an investment in the future, after the "demoralizing debacle of the Franco-Prussian War (1870-1871) …[when] politicians began to pay increased attention to their population problems [urging] physicians ...to reduce [childhood] disease" (Loudon 1993, p.1075). This built on ideas from the Enlightenment and Romanticism, which gloried in childhood, teaching that the effects of child-rearing practices would be permanent (Porter, 1997). Special hospitals were created for the specific treatment - as opposed to warehousing - of children suffering from specific diseases. New periodicals devoted to child health were launched between the 1790s and 1920s (Duffin, 1999).

Early pediatrics was primarily focused on preventing deformity and dysfunction. Bad baby care was seen as responsible for later physical deformities (Porter, 1997). Orthopaedics directed attention to spinal deformities, especially among the young. Pediatrics also came to focus on the repair of congenital abnormalities and the *prevention* of disease and disability; advocating against maternal smoking, drinking, and drug use as dangers (Duffin, 1999).

As the 20th century unfolded, scientific research developed numerous interventions with demonstrated efficacy in managing children's illnesses. These interventions included antibiotics, immunization, insulin, anesthesia and surgery, the iron lung during the 1950s

[9] Lawrence (1985) examined medical publications at the beginning of the 1900s to highlight that the shift to a scientific model and the incorporation of technologies (e.g., stethoscope, sphygmomanometer) was significantly resisted, particularly in Britain. The practice of medicine at that time was largely regarded as gentlemanly, relying on the discernment of the cultured eye and touch; without the imposition of external scientific knowledge or use of manual instruments, which were associated with the artisan trades.

polio epidemic, followed by the "invention" of cardiopulmonary resuscitation and critical care in the middle of the 20th century (Curley, 1996; Fairman & Lynaugh, 1998).

Moreover, pediatrics became influential with concepts of normal development and the physically or psychologically abnormal child (Porter, 1997), as medicine became increasingly interested in monitoring child development. French demographer Rollet has demonstrated how France developed the *carnet de santé* (i.e., health notebooks) as a means of comprehensive medical surveillance of the child's growth and development, which was directly associated with the quality of care provided by mothers (Rollet, 2004).[10]

Toward the middle of the 20th century, child psychiatry and psychology became prominent as medical domains, raising awareness of family psychodynamics and childhood problems. The expansion of the focus of pediatrics into the psychosocial and behavioural domains of childhood was partly in response to the specialty's concern about its declining status, as infant and child mortality rates were reduced (Pawluch, 1983).[11] The emotional lives of children became objects of professional inquiry and direction (Porter, 1997). Childhood behaviour and psychology became a growing field of research, emphasizing psychological over biological explanation in academic pediatrics, which was influenced by government funding (Duffin, 1999).

Particularly prominent in the lay literature was Dr. Spock's teachings on parenthood. He bolstered parents' confidence with understandable information and common

[10] Rollet's (2004) examination of these "health notebooks" highlighted that they commonly contained explicit instructions to the mother on how to properly "raise" the children; continually implying that promoting the child's growth and development was a maternal duty. That is, developmental problems in children were attributed to motherly failings.

[11] Pawluch (1983) conducted a socio-historical analysis of mid-twentieth century literature in pediatric medicine. Her analysis demonstrated how the mandate of pediatrics expended after 1950 as medical advances reduced infant and child mortality rates. Out of concern about their declining status and possible disappearance as primary care specialists, pediatricians pursued a new mandate in attending to the psycho-social and behavioral needs of children. Pawluck's analysis demonstrated how medical professional interests can exert influence on the "social construction" of medical problems.

sense; reassuring innate parental desires to please children while guiding their physical, emotional, and moral growth (Duffin, 1999).[12]

Medicalization also extended into the domain of child abuse. In the late 19th century, child abuse was initially construed as a social concern. Child abuse underwent a process of medicalization in the 1960s as pediatric radiologists developed (medical) methods for identifying and investigating this problem.[13]

Legal and Policy Milestones

Several legal and policy developments corresponded with the social shifts described above.[14] Although the American Medical Association resisted federal subsidies to establish maternal and child health programmes in the 1920s, the 1935 Social Security Act authorized federal funds for "crippled" children, maternity, and child care (Porter, 1997).

Laws preventing infant abandonment and infanticide were enacted in France in 1556, Britain in 1624, and later in other parts of Europe and North America (Baker & McCullough, 2009). However, legislation to protect children was vulnerable to interpretation according to prevailing social attitudes about their value to society at the time (Duffin, 1999).

It might be presumed that when Europe and North America tolerated infanticide, they would also tolerate abortion. There is little historical correlation between the social and legal status of the two practices. Abortion was illegal in infanticidal Nazi Germany, as

[12] As the 1900s "progressed", there was a shift away from explicit blaming of mothers for problematic child development. However, "parenting competence" has remained a significant focus of interest. Self-help books and training workshops proliferated to promote parent capacities to foster their children's growth and development (Dinkmeyer & McKay, 1989; Dreikurs & Cassell, 1990; Dreikurs & Soltz, 1964; Gordon, 1970). In contemporary times, parents are regarded – largely implicitly – as highly responsible for their child's "developmental outcome".

[13] For detailed socio-historical analyses, see Convert (1993) and Hacking (1991).

[14] A detailed analysis of relevant child law is reviewed in the following chapter.

it was in Britain, France, and North America (Baker & McCullough, 2009). In fact, at the end of the 19th century, abortions were considered unacceptable and illegal throughout Europe and North America and universally condemned by European and American professional medical societies. By the end of the 20th century, first trimester abortion was legal in almost all European States and throughout North America (Baker & McCullough, 2009)

Finally, in 1948, the United Nations passed the *Universal Declaration of Human Rights* to ensure no one would be treated as the Nazis had, not only Gypsies, homosexuals, and Jews, but also infants with disabilities and the mentally ill (Baker & McCullough, 2009).[15] In 1989, the United Nations adopted the *Convention on the Rights of the Child* (1989), designating children as a vulnerable population in need of special protections.

Provisional Hermeneutical Interpretation

As Ariès and others have argued, childhood is a social construction. Children as persons and childhood as a stage in human development have been construed in different ways through the times. This hermeneutic analysis seeks to trace how this construal has shifted over time and which SI and *horizons of significance* underlie this construal process.

Until fairly recent times, children were regarded as the father's possession and not the concern of the state or others. Abandoned newborns were "stored" in foundling hospitals without significant concern for their welfare. Just over a century ago, infant mortality was identified as a significant state concern, as family size was decreasing.

[15] In an examination of Nazi Germany atrocities, Hudson (2011) has highlighted that the killing of children with physical and intellectual disabilities were the chronological precedent, which was later extended to adults with disabilities and then to the broader racially motivated genocide. This program involved medical staff, including a number of pediatricians.

Lowered birth rates raised economic, labor, and military concerns about the future. Infant mortality acquired a new designation – shifting from being regarded as a "fact of life" to a state problem that should be solved.

Particularly noteworthy is that the moral importance that was attributed to infant mortality was rooted in a "utilitarian" ethic.[16] Initiatives to confront infant mortality were not humanitarian in nature, but rather instrumental. Saving the lives of infants was not regarded as a moral *end* in itself, but rather as a *means* to state interests as an end. Infants became "valuable" because there was an insufficient supply to meet states' political goals. Infant survival became a marker of a state's progress and a source of pride.

This corresponded with a time when medicine was turning to a scientific model and was slowly offering greater prospects for saving life. The state could turn to medicine to help solve state concerns about infant mortality, giving rise to the medicalization of childbirth followed by the medicalization of the monitoring and care of the physical and psychological health of children.

This state-mediated medicalization involved several shifts. Authority regarding the care of childbirth and children shifted from: (a) women (i.e., mothers and nurses) to men (i.e., physicians); (b) from the domain of the private (i.e., home setting, family caregivers) to the professional (i.e., institutional settings, non-family caregivers); and (c) from the family as the focus of authority and responsibility for the child to the state (i.e., through

[16] The term "utilitarian" is used here and throughout this thesis in an adapted sense. It does not refer to the work of Jeremy Bentham or John Stuart Mill on "utilitarianism" or "greatest happiness principle" (Mill, 1861/1979). The principal feature retained from Bentham and Mill is that the good of an individual is related to the good of the collective. That is, a personal good matters in terms of how it relates to the good of the broader social group. However, whereas the collective good is defined by Bentham and Mill in terms of "collective happiness", in this thesis it is defined according to the interests of the ruling state – predominantly according to economic and military state interests; as identified in the materials examined for this investigation.

state agents, policies and regulations). Moreover, medicalization transformed *children* into *patients*.

States invested in infants and children as increasingly worthy "objects" by developing services to improve their survival and welfare, implementing monetary reward programs for "infant production" by families, and instructing parents on monitoring and management of children's development and wellbeing. Indeed, parenthood was also transformed into a *means* to state interests.

The medicalization of childhood involved the formalization of state paternalism toward children. The state, through its policies, laws, regulations, and its agents (e.g., health and social services providers, administrative officers) expressed itself as the primary "parent" of its people in general and its children in specific. This is embedded in the common law principle of *parens patriae*.[17]

Within only a few decades this utilitarian-centered moral initiative toward children became challenged as some infants and children would not only be incapable of contributing significantly to State interests but could in fact become "burdens" on families and the state. As medicine saved more lives, some of the survivors were disabled. This gave rise to questions about whether all lives should be saved. On what basis should such decisions be based? This brought forth deeper rooted questions about the moral significance of children that had been largely suppressed as long as children were considered unquestionable instrumental goods for a nation.

[17] The legal principle of *parens patriae* has had a significant importance in the ongoing development of legal and ethical standards relating to childhood to the current day. This is examined in detail in the following chapter. For a broad review of *parens patriae*, see Bayer, Gostin, Jennings, & Steinbock (2007) and Payton (1992).

The "societal moral imaginaries" were undergoing tremendous shifts throughout these periods. The West was well past the Protestant Reformation, along with a series of challenges to Christian thought throughout the "scientific revolution" culminating in the powerful impact of Darwin's work (Taylor, 1989). A divine order was gradually replaced by a natural order, which science was increasingly striving to master. Darwin's theory of evolution built on contemporary ideas about inheritance, and argued for an underlying instrumental logic in the natural order – *natural selection*. The field of genetics developed within science in the early 20th century, including a period where eugenics was seen as a good use of science; genetics was regarded as a promising framework for improving the population. This had an underlying premise that some genetic compositions were better than others.

Some of these ideas were "adapted" within Nazi ideology to justify the systematic killing of sub-populations that were considered of a lesser value, such as particular races and the disabled. Eugenics has subsequently been widely rejected as an acceptable ideology. However, some have argued that the growing recognition of abortion and the withdrawal of life-sustaining treatments from disabled infants in the late-20th century and onward is based on an underlying thread of eugenic reasoning – a line of reasoning that regards life with disability as burdensome for the child, family, and society and should therefore be "prevented".[18] Moreover, the *social hygienics* movement to "improve" the

[18] Oriot (2008a; 2008b; 2008c) has highlighted that an implicit process of "screening" for "handicapped" newborns has been operating in France until recent years – possibly to this day – through a variety of measures including the active termination of life, despite the absence of a legal permissibility of euthanasia. He pointed to the concept of "arrêt de vie" that is frequently employed in the French newborn medicine literature and professional standards, which implies "termination of life" – to be distinguished from "termination of resuscitative measures". The literature highlighted by Oriot indicates that French newborn medicine had assumed a societal responsibility toward the active "prevention" of disability, even using means that were not legally permitted.

population, which emerged in the late 19th century and developed further in the 20th century, also drew on eugenic and natural selection ideology (Duffin, 1999).

These shifts set the stage for the emergence of a science-based medicine to counter illness and mortality, as well as promote population health. Health was no longer under God's dominion.

The shift to secularization also supplanted some prior theological values, such as a consideration of human life as a "sacred" divinely-regulated good, worthy of respect and dignity; setting the stage for a more instrumental utilitarian ethic.

Despite these shifts, Taylor (1989) has pointed out that the rise of secularization did not entail an erasing of the substantive moral grounds within Western societies that were previously formalized in religion. Strivings toward various forms of humanism also emerged.[19] Modernity has been widely characterized as a process of secularization, supposedly replacing prior religious moral orders with a more "liberated" affirmation of ordinary life and intellectual and political self-determination that draws on non-theological accounts of the natural and social world. Yet, Taylor has argued, Western societies have continued to contemplate persistent underlying questions about meaning and value, despite the changing moral and political discourses.

Although the medicalization of childbirth and childhood was predominantly characterized by a utilitarian ethic, questions about the sanctity of life and respect for human dignity as an end in itself persisted. This was particularly evident in the modern West in ethical responses to the atrocities of the Nazi regime, giving rise to the formulation of international statements on the respectful treatment of humans in research and other realms of life. Particularly impactful developments for this discussion were the *Declaration*

[19] As described in Taylor's analysis of the modern self, discussed in chapter 1.

of Helsinki (1964) (i.e., for medical research involving humans) as well as the United Nations *Universal Declaration of Human Rights* (1948); followed several decades later by the United Nations *Convention on the Rights of the Child* (UN Convention, 1989).

These initiatives are premised on a human rights framework – building on earlier notions of human rights – to outline basic standards required by persons to survive and develop in dignity. These rights are considered inherent to the human, inalienable, and universal. The call for the recognition of human rights challenged prior traditions of state paternalism in various domains of human life. That is, state-interest-oriented practices toward children shifted in the mid-1900s, with a growing regard for the child's interests. Children were increasingly considered to have an identity outside of the state's and parents' interests. This shift was formalized through the development of the child-centered *best interests* standard. This standard became a central notion in pediatric ethics discourse.[20]

These developments helped set the stage for what followed in the latter part of 20th century medicine, the "birth of bioethics" (Jonsen, 1998), which is examined in the next chapter.

[20] *Best interests* is examined in detail in the following chapter.

Chapter 4: The *Best Interests* of the Child

Introduction

In this chapter, I trace and examine the emergence of the *best interests* standard in relation to children. I begin with the recognition of this standard in mainstream law,[1] followed by international recognition through the United Nations *Convention on the Rights of the Child* and finally within formal ethical normative development. In the final section, I review these developments through a hermeneutical analysis.

As in the previous chapter, references are cited heavily in this chapter as well to indicate the sources of the historical developments that are highlighted.

Legal Recognition of the *Best Interests* of the Child

In early history (e.g., Roman Empire), fathers held absolute authority over their children, recognized through the legal principle of *patria potestas* (LaFave, 1989). Fathers also held power over the life and death of their children in England until at least the tenth century. By the seventeenth century, while it was prohibited for parents to murder their child; all other child maltreatment was apparently permitted. By the late nineteenth century, there was a gradually increasing view that children should not be abused by their parents (McGough & Shindell, 1978).

The shift toward growing state interest in child welfare was grounded predominantly in the legal principle of *parens patriae* (Custer, 1978). This principle in England, translated literally as "father of the nation", refers to the power of the state to

[1] The emergence of *best interests* in child law is examined by drawing on published historical analyses of child law, focusing predominantly on North America and Britain.

intervene into the matters of private citizens. Early on, this related primarily to the state's protection of the financial health of its subjects. When fathers died without having chosen a guardian for their minor children, the state collected rent and profits from land held by minors. In early application of this principle, it has been argued that the state's motivation was primarily financial self-interest (Abramowicz, 1999; Custer, 1978).

By the end of the seventeenth century, the judiciary used *parens patriae* to justify intervening in cases involving the guardianship of infants, apparently without regard for state financial interests. Fathers were given the power to appoint a guardian for their minor children; in turn, courts assumed the power to enforce these wishes for the benefit of the child (Custer, 1978). *Parens patriae* was now used for the *care* of minors, as opposed to protecting the state's financial goals. The state was increasingly regarded as a protective authority for minors.

Early in the nineteenth century, the scope of *parens patriae* was widened through the courts so they could intervene "for the express purpose of promoting the moral welfare of children, regardless of the wealth or position of their parents" (Custer, 1978, p.206). Courts assumed the right to supervise fathers and to modify custody arrangements. Fatherhood became viewed as a trust that the state and the courts could oversee. However, although court involvement in custody battles became increasingly common at the beginning of the nineteenth century, the courts actually reinforced the view that fathers held absolute custody rights over their children (Abramowicz, 1999).

Children began to be considered in decisions affecting them in the first half of the nineteenth century (Dolgin, 1996). Children were beginning to be seen to have interests independent from their parents and that they needed special consideration.

Children and families came to be viewed more "affectionately" at the beginning of the nineteenth century in North America. That is, the emotional needs of children were gradually given greater weight (Dolgin, 1996). Accordingly, consideration of the child's *best interests* came to be used as a standard in custody cases, limiting the previously quasi-absolute rights of fathers regarding their children.[2] However, perceptions of what constitutes children's *best interests* have changed over time, in line with ongoing changes in social norms and constructions of childhood.

The *Tender Years Doctrine.*

Initially, court orders regarding child custody (e.g., following divorce or death), were based almost exclusively on the income generated by each parent. Children were therefore generally seen as assets belonging to their fathers (Woodhouse, 1999-2000). Over time, the *Tender Years Doctrine* emerged out of concern for the welfare of the child. This set the stage for the subsequent conception of the child's *best interests* standard.

Social changes in the nineteenth century commonly resulted in men working farther away from home and the home came to be seen as the women's domain. The need for discipline and guidance, traditionally associated with the father's role, was considered secondary to the need for love and nurturance presumably associated with the mother's role (LaFave, 1989).

The *Tender Years Doctrine* replaced the presumption in favour of fathers in custody disputes (Woodhouse, 1999-2000). It was increasingly believed that young children needed

[2] The sources examined in this chapter convey that this standard implies a regard for the child's well-being, needs, growth and development, dignity, among other considerations; as demonstrated throughout this chapter. It is unclear, however, how the term "interests" was chosen among other possible terms. I have been unable to trace how this term (i.e., "interests") was selected for this particular standard.

the "nurturing care" of their mothers. Thus, children were no longer treated as assets belonging to their fathers and mothers would often obtain child custody because of the presumed vulnerability of their children.

The *Tender Years Doctrine* is a particular historical application of the *best interests* standard. It was applied in custody disputes in North America until the 1960s (Artis, 2004). This *Doctrine* also contributed to the view that custody decisions should be based on individualized assessments of the welfare of the child.

Children's *best interests.*

It was increasingly recognized in the 1960s and 1970s that men were also able to care for infants (Artis, 2004). It therefore became acceptable for judges to decide custody cases on an individual basis, without *a priori* gender biases, in terms of the child's *best interests*. Judges were required to compare the overall merits of each parent for each custody case.

It became accepted in the courts that children's *best interests* could be evaluated "objectively", by including professionals (e.g., psychologists, social workers) in judicial custody disputes (Woodhouse, 1999-2000). *Best interests* allowed judges to effectively consider all relevant factors in custody cases, as no particular "primary" criteria had been specified. This gave significant discretion to the judiciary; as judges used highly biased standards in evaluating parental fitness (Artis, 2004). Some jurisdictions therefore adopted legislative guidelines to try to make this process more "objective". Generally, *best interests* judgments currently tend to "favour" mothers in North America, who are awarded custody in over eighty percent of cases (Artis, 2004).

In recent years, there has been a slowly growing recognition of the "child's own voice" in determining their *best interests*. This has been linked to child psychology research

demonstrating that children's moral reasoning capacities are more sophisticated than has been commonly accepted.[3] The weight accorded to children's opinions to date has depended primarily on their level of maturity and the seriousness of the decision being made.

By the late twentieth century and onward, *best interests* has been adapted into a broad standard for all aspects of children's well-being, including medical decisions, youth criminal justice, child welfare, adoption, education, social issues, and immigration (Logan, 2008). For example, youth protection law allows for parents' rights to be impinged upon to protect children who may be in danger. In education, children's interests include rights to freedom of expression, religion, non-discrimination, access to information, and protection from harm; which applies both to individual children and to children as a group. In medical decision-making, *best interests* is the clearly accepted overriding standard for treatment decision-making relating to children.

United Nations *Convention on the Rights of the Child*

The preceding section outlined how there was a major shift toward the child's *best interests* as the overriding standard for all matters relating to children during the twentieth century. This shift was driven by a number of forces. Among these, a significant source was the post-war examination of the treatment of humans and numerous articulations of human rights.

[3] A vast and diverse body of literature supports this assertion. This includes empirical research (Bluebond-Langner, 1978; McPherson, 2007), reflective clinical analyses (Coles, 1986; Sourkes, 1995), review statements (Harrison, Kenny, Sidarous, & Rowell, 1997; Kenny, Downie, & Harrison, 2008), theoretical/normative articulations (Alderson, Sutcliffe, & Curtis, 2006; Kagan & Lamb, 1987; Ross, 1998; 2006; Weir & Peters, 1997), and court testimonials (Melton, 1999).

For example, the Nuremberg Trials helped push forward a major shift in the development of standards for the respectful treatment of humans in research (Nuremberg Code, 1949). The United Nations (UN) produced numerous important statements on human rights, which were both (a) expressive of these mid-century shifts in views of humans as moral ends in themselves and not merely means toward the ends of states and (b) attempts to direct future changes in the treatment of humans internationally. Particularly noteworthy was the *UN Universal Declaration of Human Rights* (1948) – followed later by the *UN Convention on the Rights of the Child* (UN Convention, 1989)[4]. The latter is the most widely ratified international normative convention.

This UN Convention stipulates a wide range of rights that should be accorded to children, requiring that all actions regarding children must maintain the child's *best interests* as a primary consideration. "In all actions concerning children, whether undertaken by public or private social welfare institutions, courts of law, administrative authorities or legislative bodies, the *best interests* of the child shall be a primary consideration" (UN Convention, 1989, article 3).

The UN Convention defines "child" as a human being below the age of eighteen years unless majority is attained earlier under the law applicable to the child.

The UN Convention asserts that children have a right to:

- life (article 6);
- protection against discrimination (article 2);
- not be separated from his/her parents (article 9);
- express views freely and have an opportunity to be heard (article 12);

[4] Hereafter referred to as UN Convention.

- freedom of thought, conscience and religion (article 14);
- access information and material from diverse sources (article 17);
- protection from abuse (article 19);
- protection when deprived of family (article 20);
- adoption based on his/her *best interests* (article 21);
- protection for child-refugees (article 22);
- special protections for the child who is disabled (article 23);
- enjoyment of the highest attainable standard of health and to facilities for the treatment of illness and rehabilitation of health **(a**rticle 24);
- a standard of living adequate for the child's physical, mental, spiritual, moral, and social development (article 27);
- education **(a**rticles 28-29);
- enjoyment of own minority culture (article 30);
- rest and leisure (article 31);
- protection from economic exploitation **(a**rticle 32);
- protection from illicit drugs **(a**rticle 33);
- protection from sexual exploitation **(a**rticle 34);
- protection from abduction (article 35);
- protection from all other exploitation (article 36);
- protection from torture, capital punishment, life imprisonment, and unlawful imprisonment (article 37);
- respect for a minimum age of fifteen years for participation in war (article 38);

- promotion of recovery and reintegration for children who are victims of neglect, exploitation, abuse, torture, or armed conflicts (article 39); and
- protection in penal law (article 40).

The UN Convention also stipulates that parents have responsibilities, rights, and duties to provide direction and guidance (article 5) as well as the primary responsibility for the upbringing and development of the child, with the *best interests* of the child as their primary concern (article 18).

Recognition of Child's *Best Interests* in Formal Ethical Norms

Alongside the development of legal norms regarding the child's *best interests* from the mid-twentieth century onward, emerged the articulation of formal ethical norms for medical care and research involving children. These too have been centered on the *best interests* standard. The development of contemporary research ethics standards are largely rooted in the 1949 Nuremberg Code (1949), following the human experimentation atrocities committed during World War II. This was followed by the development of additional international research ethics standards, such as the 1964 *Helsinki Declaration by the World Medical Association* (WMA Declaration of Helsinki, 1964) as well as nation-specific standards.

The formal development of contemporary ethical standards in North American for medical care and research involving humans were most substantively launched in the Unites States during the late 1970s and early 1980s through a series of reports prepared by various American National Commissions. The Reports that were principally reviewed for the purposes of this analysis are:

- Research Involving Children. *The National Commission for the Protection of Human Subjects of biomedical and behavioural research* (Research Involving Children, 1977);
- The Belmont Report. *Ethical Principles and Guidelines for the protection of human subjects of research. The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research* **(**The Belmont Report, 1979);
- Making Health Care Decisions. *Presidents Commission for the Study of Ethical Problems in Medicine and Biomedical and Behavioural Research* (Making Health Care Decisions, 1982);
- Summing Up. *Final Report on Studies of the Ethical and legal Problems in Medicine and Biomedical and Behavioural Research* (Summing Up, 1983).

The development of these norms was linked to international normative development initiatives described above, as well as emerging concerns about the treatment of humans in clinical care and research in the United States. This period of extraordinary normative development corresponded with what is generally considered to be the "birth of bioethics" in North America.[5]

Norms relating specifically to clinical care and research involving children are outlined below. These highlight the emergence of *best interests* in North American pediatric medicine.

Clinical care of children.

For clinical care involving a child who is unable to protect him/herself, surrogate decision-makers are required to protect the child's "vital interests" (Summing Up, 1983).[6] "Decisions must be made by others based upon a judgment of what the person would have chosen if he or she were able to do so or, if that is not clear, what would be most likely to

[5] As stated in the previous chapter, for a thorough review of the "origins" and development of North American bioethics, see Jonsen (1998).

[6] This review highlights the subtle variations that were used initially in articulating an ethical standard for children (e.g., vital interests, interests, goals, well-being). Over time, the term *best interests* became a more "stabilized" term for stating the standard to be used for children, as well as some adults.

promote the incapacitated person's well-being" (Summing Up, 1983, p.69). It is the "responsibility of the health care professional to recognise the incapacity and to find another way to reach a decision that will advance the patient's goals and interests" (Making Health Care Decisions, 1982, p.55). In short, it is recognized that for children considered incapable of making "self-protective" decisions,[7] surrogate decision-makers are the responsible decision-makers for children. These decision-makers should decide according to the child's *best interests* – a concept that is not explicitly defined.[8]

Research with children.

In the context of research with children, research ethics standards highlight that the state has a responsibility to ensure children's *best interests* are protected. Although parents are generally considered to be the best protectors of their children (Research Involving Children, 1977), parents' interests may conflict with those of children. It is recognized that courts have limited the authority of parents as protector and judge of their children's *best interest* because parental or guardian interests may sometimes conflict with the best interests of their children (Research Involving Children, 1977). "The function of third-party consent is not to respect the child as an autonomous moral agent but to safeguard the child's best interest" (Research Involving Children, 1977, p.114). Parents are expected to act in the *best interest*s of children to provide "attention and kindness to the defenseless and powerless" (Research Involving Children, 1977, p.115). It is presumed that parents and society act in the *best interests* of the child in order to "protect children from their own judgment and to insist that their behaviour conform to what is determined to be in their own

[7] However, "incapable" is not explicitly defined.
[8] Footnote #10 in the Introduction provides an overview of the *best interests* standard in current-day pediatric medicine.

best interests, in the best interests of the family unit, or in the best interest of the state" (Research Involving Children, 1977, p.73).

In short, decisions relating to children's participation in research need to be centered on the child-participant's *best interests*. These research ethics standards have also outlined a number of related norms regarding the participation of children in research. It is recognized that involving children in research is important for the health and well-being of all children and that such research can be conducted in an ethical manner (Research Involving Children, 1977). Research is necessary to learn about normal development as well as disease states in children (Research Involving Children, 1977). Children who are wards of the state or are institutionalized are considered particularly vulnerable and in need of greater protection in research.

Particularly noteworthy is that some research ethics norms recognize children as active "moral subjects" capable of understanding: the implications and potential benefits of participating in research should be explained to the child and the child should be asked if he/she wishes to participate (i.e., assent) or to decline. That is, it is important to respect the developing capacities of children for informed choice; they exhibit varying capacities for understanding and consent (Research Involving Children, 1977). At seven years of age or older children are generally capable of understanding research and of indicating their wishes regarding participation. Their assent should be required in addition to parental permission (Research Involving Children, 1977).[9] Children's objection to participation in research should be respected. "Even the objection of a very young child should be binding

[9] Contrary to consent, for which explicit conditions have been established (e.g., consent should be informed and free – i.e., not coerced), assent has not been defined in a widely accepted manner. Assent can be practiced in research as well as clinical care involving children. In general, assent implies that the child has received information about the proposed study (or the proposed treatment for clinical care) adapted to the child's capacity to understand and that the child voluntarily cooperates with the required measures. An expression of objection or dissent would indicate the absence of assent.

except for situations in which the research involves a therapeutic intervention that is unavailable outside the research context" (Research Involving Children, 1977, 129). Finally, it is argued that involvement in research can have an important educational value for the child-participants themselves (Research Involving Children, 1977).

It is interesting that this recognition of the "child's voice" in these early norms is most explicitly developed in research ethics, where it ensures children can be protected from potential harms for activities not oriented toward their own interests, rather than clinical care norms where clinical care is considered to serve the child's interests, regardless of the child's expressed preferences.

Summary comments.

In the three decades that have followed since these initial formulations of pediatric ethics standards, these norms have remained relatively unchanged. The central standard that orients all decisions affecting children is the child's *best interests* – be it for medical care, research, schooling, adoption, parental custody decisions, or youth protection. There have been significant disputes regarding the respective authority of parents, physicians, and state bodies such as the courts or youth protective agencies that have sided in different ways over the years, consistently based on *best interests* arguments. In recent years, there has been a slowly growing recognition of the child's capacity to act as an autonomous decision-maker particularly in relation to some medical treatment decisions.[10]

[10] For example, section 14 of the *Civil Code of Quebec* (1994) indicates that starting at the age 14 years, a minor has the right to consent to medical care, without parental corroboration and without being informed about the minor's consent. However, some conditions are applied to this right. If the minor is admitted to a hospital or social services setting for 12 hours or more, then parents are to be informed of that fact. The minor's right to consent is restricted to medical treatments required by the minor's state of health (e.g., this does not apply to unneeded cosmetic surgery). Moreover, if the minor refuses required medical care and the

A persistent concern throughout the evolution of contemporary pediatric ethics has been how the child's *best interests* should be defined and who can best determine a child's *best interests*.

Preliminary Hermeneutical Analysis[11]

As stated before, the mid-twentieth century was a significant shifting point in terms of ethical frameworks relating to medicine – particularly in North America. Post-World War II concerns emerged about the potential mistreatment of humans in research, when research is conducted without externally agreed-upon ethical standards. In clinical care, initial utilitarian frameworks for pediatric medicine were running up against ethical concerns when some medical outcomes could be considered of benefit for a patient but not necessarily beneficial for the state; for example, persons with significant disability.

One prominent approach to addressing such concerns was a legally-based specification and promotion of particular human rights, such as the United Nations initiatives. International statements on human rights and national law reforms explicitly recognizing fundamental human rights significantly challenged existing state and medical paternalism regarding medical care and research. Individual persons became recognized as bearers of rights regarding: their choices (or refusals) for medical care or research; privacy and confidentiality; the respectful treatment of human bodies; and protection from discrimination and injustice; among other rights.

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refusal can entail serious risk for the minor, then in some circumstances the parents may be able to consent to such treatment despite the minor's refusal.

[11] The discussion that follows outlines an initial examination of the normative developments relating to the *best interests* standard described in the preceding sections. This examination is further developed in the following chapter, particularly in relation to the Taylorian notions discussed in chapter 2.

These initiatives can be considered a form of "moral universalism" – striving to specify and promote universal standards for all persons across contexts; even internationally. This moral universalism was argued in terms of an underlying substantive "humanitarian ethic"; that is, regardless of local ideologies or practices, every person is considered entitled to respect and a uniform set of protections.

The corresponding "birth of bioethics" appeared to follow a similar ethical orientation, both through the significant concentration of efforts toward the formation of fundamental ethical norms that should be applied across medical practices and research, but also in terms of the ethical framework that was to emerge as the clearly dominant framework for ethical care: *principlism*. Although principlism has evolved in various forms, its most popular formulation is commonly referred to as the "Georgetown Mantra" of bioethics, centered on the principles of autonomy, beneficence, non-maleficence, and justice (Beauchamp & Childress, 2001).[12] Although a significant body of literature has been published to challenge or defend the merits of principlism,[13] this has been the dominant ethical framework in North American medicine.[14]

Although the dominant principlist framework involves four principles (i.e., autonomy, beneficence, non-maleficence, justice) that should be counterbalanced with each

[12] Beauchamp and Childress (2001) are widely regarded as the leading proponents of principlism in bioethics, largely through their highly popular book *Principles of biomedical ethics*, which was printed in its fifth edition in 2001. However, their "four-principles" articulation of principlism drew significantly on the Belmont Report (1979), which is generally regarded as the first formal statement of principlism in what was to become known as bioethics. The Belmont Report identified three ethical principles for biomedical and behavioral research involving human subjects: (a) respect for persons; (b) beneficence; and (c) justice.

[13] For examples, see: Clouser & Gert (1990); DuBose, Hamel, & O'Connell (1994); *Kennedy Institute of Ethics Journal* (1995).

[14] The term "dominant" is used here to imply that *principlism* is recognized by the cited critics as the most widely taught and practiced bioethical framework. This does not, however, also imply that it is necessarily the strongest or most respect-worthy framework.

other,[15] "respect for autonomy" has emerged as a particularly prominent principle; relating to deeply foundational notions of persons as self-determining agents. This was decidedly crucial toward the contemporary formulation of the doctrine of informed consent; that persons are entitled to receive relevant information regarding proposed medical care or research and that they should be able to choose or refuse as they wish, free from any coercion.[16]

This centering of North American bioethics on patient autonomy confronts complex challenges when the patient is a child. The earlier sections of this chapter have highlighted that children are generally not considered "capable" of being autonomous; they have been considered formally dependent rather than independent. As dependents, they were regarded as a form of paternal property in early times, shifting during the last century into incapable and dependent "humans in becoming" in need of protection.[17] Parents were initially regarded as bearers of "ownership authority" over their children, shifting to responsible custodians – responsible for ensuring the well-being and ongoing growth and development of the child. Toward this end, parents are granted the authority to develop the conditions for these outcomes.

Parental authority regarding children is considered conditional by the state; conditional on the parents' fulfillment of state standards for children's welfare – invoking "youth protective" measures that can override parental authority when state officials judge that parents are not adequately fulfilling parenting expectations. State standards – which

[15] They should be balanced by seeking "reflective equilibrium", as adapted by Beauchamp and Childress (2001).
[16] Stoljar (2011) has drawn on Taylor's analysis of agency to argue that informed consent is not sufficient for patient autonomy, highlighting a "relational" conception of autonomy. She argues that informed consent is an "opportunity" concept whereas autonomy is an "exercise" concept; that informed consent requires merely weak evaluation and not strong evaluation.
[17] This concept is discussed in detail in the next chapter. Lee's (2001) socio-historical research has made especially important contributions in this domain.

have been systematically formalized within legal norms - are generally stated as based on children's *best interests*. This legal framework for children is essentially consistent with the ethical framework for children in North American bioethics – as demonstrated in the ethical norms developed by the various American President's Commission reports discussed above.

In short, the dominant ethical and legal framework regarding children in North America is based on the child's *best interests*.[18] Three principal issues emerge from the above discussion. First, it is noteworthy that ethical and legal norms converge virtually entirely with regards to the medical care of children. Second, also noteworthy is the contemporary construal of the child as incapable, dependent, and in need of protection; with corresponding debates about how the responsibility and authority for child protection should be assigned – and a small emerging literature suggesting that the child's own voice should be considered. Finally, the ambiguous nature of *best interests* persists, as there is no widely agreed-upon definition of this foundational concept. These three issues are discussed below.[19]

The convergence of legal and ethical norms.

On the surface, it is understandable that ethical and legal norms would converge with regards to medical care and research with children.[20] On the other hand, whereas child law seeks to define and protect the rights of children as a vulnerable population by establishing

[18] For current discussions of the contemporary North American *best interests* standard, see: Kopelman (2010) and Sayeed (2010). The reader is also referred to the overview discussions of *best interests* outlined in the Introduction of this thesis.

[19] These issues are examined in greater detail in the following chapter, as "moral malaises" in light of Taylor's hermeneutical analysis of modernity.

[20] Indeed, this convergence has been recognized in medicine in general, not just in pediatrics. For detailed discussions of the inter-relations of ethics and law in medicine, see Schneider (1994; 1996). For a specific focus on pediatric medicine, see Sayeed (2010).

best interests as the central legal standard for determining matters affecting children, this seems to disregard other "goods" that are understandably absent from legal norms but surprisingly absent from ethical norms.

For example, in assessing a child-patient's *best interests*, it is not uncommon that these may conflict with the interests of siblings, parents, families, HCP, and limited societal resources. Let us consider the case of a newborn infant with severe brain injury acquired during labour and delivery complications, where it is predicted that the infant will be significantly dependent for life, requiring complex continuous care at home. Yet, the infant is able to demonstrate pleasure and comfort when provided with attentive continuous care. It can be concluded that the benefits derived from this continuous care clearly outweigh the burdens and that it is in the infant's *best interests* to sustain life and provide around-the-clock complex care at home.[21] Many families have in fact provided such care and have reported convincing accounts of good "quality of life" for the child.[22]

In such cases, parents or HCP can also identify that although such a plan may be favourable for the child-patient, the potentially unfavourable impact for the other children

[21] For a detailed account of families' lives when caring for a child with significant disability, see: Sobo (2010).

[22] In Carnevale, Alexander, Davis, Rennick, & Troini (2006), a qualitative study was conducted to examine the moral experiences of families with children requiring mechanically-assisted ventilation (i.e., respirators) at home. The study included 12 families (i.e., 38 family members) recruited through the Quebec Program for Home Ventilatory Assistance. Although a significant degree of distress and difficulties were reported in the lives of the disabled children and their families, there were also remarkable accounts of pleasure and enrichment among the children and their families (Carnevale, Alexander, Davis, Rennick, & Troini, 2006). Despite the children's complex medical conditions and the extraordinary medical devices required to assist their vital and basic bodily functions, there was no doubt or question among these children and families about the worthiness or quality of the children's lives. Their lives were complicated and challenging, but it was all worth it – according to the study participants. In fact, the greatest hardships that they endured were not based on the children's medical condition or required treatments, but rather on the significant physical and social barriers – and corresponding stigmatization and discrimination - which they faced on a daily basis in their communities. This study led to the filming of a documentary that further explores these points. The documentary is titled *Living with Miracles* (see weblink: http://skyworksfoundation.org/documentaries/productions/lwm/index.html).

in the family, parents, and overall family life are not given any consideration by leading ethical norms for the medical care of children.

These other interests tend to be regarded as "conflicts of interests," which HCP are required to monitor, to ensure parents are properly acting as patient-centered decision-makers, putting to the side the interests of others affected by such decisions. However, clinical practice standards in pediatrics, which define good standards of care, have argued that pediatric care should be family-centered; that HCP should regard the family as a whole system and attend to the ensemble of health-related needs that may emerge.[23]

Formal pediatric ethics standards are child-patient-centered, apparently in consideration of these children as particularly vulnerable and in need of special protections. It is however striking that family-centered-care standards of pediatric medical practice are not given any consideration whatsoever in pediatric ethics norms. For example, parents are regarded exclusively as "surrogate decision-makers" for the child and not as persons whose lives are also morally meaningful – that they are not merely a source of competing interests. Pediatric clinicians are accustomed to the complex multiplicity of goods involved in the care of children, yet these "other goods" are systematically absent from formal statements of pediatric ethical standards.[24]

This phenomenon seems rooted in the prevalence of "deontological" ethical frameworks in medical care, where "the good" is construed primarily within a framework of "do's and don't's", codified in various codes of ethics and other ethics statements.[25] This results in a conception of bioethics that strongly resembles the structure of law – centered

[23] For an example of a discussion of "family centered care", see American Academy of Pediatrics (2003).
[24] This assertion is corroborated by the principal ethical statements of the American Academy of Pediatrics and the Canadian Bioethics Society (AAP, 1994; 1995; CPS, 2004).
[25] For an explicit discussion by Taylor of this phenomenon, see Taylor, Carnevale, & Weinstock (2011).

on the specification of rights or entitlements and corresponding obligations. Although a diversity of ethical frameworks were developed within bioethics by the end of the twentieth century (e.g., relational ethics, narrative ethics, ethic of care, feminist ethics, casuistry, hermeneutic ethics, among others), these are not acknowledged in the most widely-recognized articulations of ethical care for children, such as the previously-cited ethical statements of the American Academy of Pediatrics and the Canadian Bioethics Society (AAP, 1994; 1995; CPS, 2004).

The dominant pediatric ethical framework is essentially "legalistic" (i.e., law-like). This may be attributable to the dominant force that law has played in the North American SI in defining ethical outlooks (Taylor, 2004). It has been commonplace in bioethical practice and education to refer to court decisions as solution sources for complex bioethical problems; where the courts are regarded as the ultimate moral authority.

This phenomenon is congruent with Taylor's critique of modern Western moral outlooks in secular societies (Taylor, 1989; 2007), where there are no agreed-upon substantive "value grounds" that can help orient communities or societies in their examination of presenting ethical concerns. Whereas in the past, religious doctrine and related governing bodies were common sources of moral authority, in secular societies the courts have become the ultimate moral authorities, drawing on available legal doctrine, jurisprudence, and legislation – centered predominantly on formally specified rights and obligations as well as legal procedures. This results in an "individualism-centered" prevailing moral order, where the "good" is defined by what autonomous (adult) agents state is good for them.

The child as incapable and dependent.

Throughout the historical overview discussed above, a major continuing theme is the conception of children as non-autonomous, incapable, and dependent with the later addition of the view of children as vulnerable and in need of protection. Children were initially regarded as fathers' "properties". The state became involved in assuming authority over children – initially in continuity with fathers' authority by assisting in carrying out fathers' estate management wishes. Then, in recent decades, the state's focus shifted to the child's own interests, where the state acted as an autonomous father (i.e, *parens patriae*), independent of the father's interests to intervene when it judged that parents were not parenting adequately.

In current times, parents (including mothers) are generally regarded as the primary "custodians" of their children – but their parenting is expected to be focused on promoting the children's well-being. For example, parents are considered responsible for ensuring their children's health, education, and promoting their overall growth and development. In line with the Western valuing of autonomy, it is also recognized that parents should have significant independent discretion in the manner that they raise "their" children; e.g., that the state should not impose external moral values. Parents can and should exercise their chosen moral/religious system as their framework for child-rearing. Parents are accorded significant latitude in deciding which forms of discipline they use in parenting, as long as they are not considered abusive. That is, it is widely recognized that the state should not be involved in private matters of the home.

However, as children have become viewed as "ends" in themselves, and not as "means" to their parents' ends, Western states have developed youth protection legislation that allows "state agents" (e.g., youth protection workers) to intervene in family matters,

monitor and judge parenting in terms of how well children's interests are fulfilled, and override parental authority by assuming responsibility (temporarily or long-term) for the child's well-being.[26]

The current framework for children has resulted in a complex debate regarding the extent and conditions for parental versus state authority regarding children's interests. Parents are generally considered the responsible "authorities" for their children. However, state agents can override parental authority under exceptional circumstances. Thus parents are the assumed authorities; but under exceptional circumstances – which have been defined by the state through legislation and administrative procedures – the state can exercise its own ultimate authority over its population and can override parents.

In contemporary pediatric medicine, parents are generally regarded the decision-makers for their children's care. Parental authority for children's medical care decision-making has emerged as historically significant against a backdrop of medical paternalism. Until the development of medical ethical standards in the mid-twentieth century that recognized patient autonomy and free and informed consent, physicians acted as the primary decisional agents for all patients; children and adults. Until the implementation of state-funded health care in North America (albeit in a very limited manner in the United States), physicians acted largely as private entrepreneurs with a general requirement that they practice in accordance with the recognized standards of medicine, although the latter standards were weakly "enforced".

In early pediatric medicine, the child's *best interests* regarding medical care was decided by the physician.[27] With the emergence of the mid-twentieth century medical

[26] For example, youth protective measures in Quebec are regulated through the *Youth Protection Act*, RSQ, c P-34.

ethical norms described above, parents have become the recognized formal decision-makers for their children's care in North America.

However, the state monitoring and intervention youth protective framework outlined above is applied in pediatric medicine as well. If parents' treatment choices are considered contrary to a child's *best interests*, then physicians can seek court authorization to provide the care that they consider necessary. In fact, a recent study indicated that in such contexts, courts more commonly side with physicians (Ridgway, 2004).[28] It is therefore interesting to note that in pediatric medicine, parents are considered the day-to-day decisional agents; however, health care professionals (HCP) are required to monitor parent decisions in relation to the children's interests and challenge such decisions when they appear contrary to children's interests.

When physicians or other HCP assess that parents' decisions or actions are contrary to children's interests, it is also noteworthy that the former cannot unilaterally override parental authority. They require court authorization or youth protection agents' interventions. Whereas, physicians used to hold significant decision-making discretion, if not autonomy, in the care of children until the mid-twentieth century shifts, while the state was assuming clearer authority in its authority over children; in the current day, physicians hold very limited direct decision-making authority for children, although they seem to have a significant influence on the decisions of the courts (Ridgway, 2004).

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[27] To this day, in France, the physician is still considered the responsible decisional authority for medical treatment decisions involving life-sustaining therapies in pediatrics (Hubert, Canoui, Cremer, Leclerc, et al., 2005).

[28] Ridgway (2004) examined published court opinions resulting from 50 parent-physician disagreements over the care of children, which led to physician requests for court intervention. The opinions describe 66 children from 20 states. Physicians prevailed at the initial decision in 88% of the disputes and at the final decision in 80% of the cases. Courts acknowledged the pediatric patients' views in only 10 of the disputes (i.e., 9 of the 19 cases involving adolescents and 1 of the 31 cases involving children younger than 12 years). For most cases, the petitioning physicians provided the only source of scientific information.

Within this ongoing debate between state and parents regarding children's best "guardians" of their interests, a more recent line of discussion has emerged regarding the "voice of the child";[29] what significance should be accorded to the child's own views, wishes, and preferences in various matters affecting them, including medical care?

For example, in medical research it has become widely accepted that a child-participant's assent should be solicited and that a child's refusal to participate in non-therapeutic research should be respected. There is a growing recognition that a child-patient's assent should be obtained in pediatric medical care as well, with a growing recognition that some youths are capable of providing consent for treatment on their own.[30]

The latter is largely drawn from empirical research demonstrating that children's capabilities to engage in medical decision-making have been significantly under-appreciated.[31] As discussed above, in some jurisdictions such as Quebec, this has been translated into legislation that recognizes consent for medical decision-making among youths starting at the age of 14 years; with selected conditions that apply (*Civil Code of Quebec*, 1994, article 14).

This discourse calling for attention to the "voice of the child" expresses a further shift in societal understandings of childhood; following the early shift from child as a form of paternal property to an incapable person with his/her own interests that require protection, seen as dependent throughout these shifts; to a person with a developing sense

[29] See footnote #3 in this chapter regarding children's moral reasoning capacities, which outlines relevant published empirical research, reflective clinical analyses, review statements, theoretical/normative articulations, and court testimonials.
[30] For example, seeking the child's views and giving consideration to his/her views – and in some cases seeking a minor's consent to treatment – is recognized in American Academy of Pediatrics and Canadian Pediatric Society statements on treatment decision-making in pediatrics (AAP, 1994; 1995; CPS, 2004).
[31] As stated in footnote #3 in this chapter, see: Alderson, et al. (2006); Bluebond-Langner (1978); Coles (1986); Harrison et al. (1997); Kagan & Lamb (1987); Kenny et al. (1998); McPherson (2007); Melton (1999); Ross (1998; 2006); Sourkes (1995); Weir & Peters (1997).

of understanding and autonomy that should be recognized at least through assent, if not (relatively) independent consent. Whereas earlier shifts expressed broader societal shifts toward a more "humanitarian" recognition of children – regarding children as incapable dependents in need of protection, sometimes from their parents or even the state;[32] more recent shifts involve an extension of the deeply-rooted Western moral ideal of respect for autonomy. These later initiatives express reservations about some "youth protective" measures as possibly infringing upon youth's potentially legitimate autonomy. Indeed, the age threshold that distinguishes childhood from adulthood is clearly a social construction, which is the subject of some ongoing re-consideration. This childhood-adulthood distinction has been described as a division between "human beings" and "human becomings", whereby children are only recognized as on course toward becoming future independent capable human beings and therefore not meriting the full considerations of "human-hood" accorded to adults.[33]

Throughout history, children have been the focus of ongoing debates regarding whose authority they fall under, with more recent examinations of the standards that should apply for exercising this authority. The prevailing Western view is that children are vulnerable because of their undeveloped capacities to formulate and assert their own interests and that they are entitled to special protections of their interests. The Western context that is highly centered on respect for personal autonomy, generally extends this respect to families; the domain of family life is generally considered private and to be shaped independent of any state intervention. Thus parenting is generally considered

[32] That is, international statements on the rights of children (e.g., UN Convention, 1989) seek to ensure that all states around the world accord children the same minimal recognition and rights.
[33] Lee's (2001) socio-historical examination of childhood and the distinctions between adulthood and childhood as "human beings" and "human becomings" respectively, as well as other related research, is reviewed in detail in the next chapter.

outside the sphere of state activity – but within certain limits. States commonly stipulate minimal parenting standards, which the state reserves the right to monitor and enforce.[34]

Finally, it is argued by some that respect for personal autonomy should be extended to childhood, recognizing that children can and should act as their own decisional agents.[35]

The current *Social Imaginary* (Taylor, 2004) consists of a blend of ideas and practices from state authoritarian models and respect for personal and family autonomy, rooted in an espoused underlying humanitarian vision toward the protection of children. This espoused humanitarian outlook sometimes collides with other societal values - such as efficient use of limited resources – sparking some current debates over resource allocation, with a covert contestation of society's commitment to some persons, such as the significantly disabled.[36] This debate has been largely implicit, but deeply underlies the following discussion regarding unsettled conceptions of the child's *best interests*.

The ambiguous nature of best interests.

A further concern surrounding the *best interests* standard is that there is no agreed-upon definition of this concept. In medical decision-making for adults, it is widely recognized that patients can express highly diverse treatment preferences (e.g., yes or no to blood transfusions) and that these preferences should be respected as long as the adult patient is considered legally capable.

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[34] Some philosophical investigations have examined the family and parenting as a realm of ethical inquiry. For example, a theme issue of the journal *Ethics and Social Welfare* titled *Ethical Perspectives on Contemporary Living Arrangements and Parenthood* (*Family Values*, 2012) includes papers on the moral value of families by Gheaus, the future of the family by Archard, the family and neoliberalism by Brecher, shared parenting by Cook, the social politics of breastfeeding by Smyth, licensing of parents to protect children by Wispelaere and Weinstock, and maternity leaves by Robeyns.

[35] For example, see: Alderson, et al. (2006); Harrison et al. (1997); Kenny et al. (1998); McPherson (2007); Melton (1999); Ross (1998; 2006).

[36] See Levine (2005) for a discussion of how conflicting social values regarding childhood disability result in social isolation and injustice.

For children, the *best interests* standard is intended to serve as an essentially "objective" standard, requiring responsible decision-makers to act in terms of what is best for the child and not what the decision-maker might want for the child. In cases of concern, the courts serve as the ultimate authority in determining what is best for an individual child.

Yet, how should *best interests* be defined by these decisional agents? Some considerations toward determining the child's *best interests* have been published. Although there is a growing recognition that the child's expressed preferences should be taken into consideration, the most developed conception of *best interests* relates to the proportional balance of benefits and burdens entailed by each available option for the child. For example, the medical treatment option that offers the greatest proportion of benefits in relation to burdens for a child is considered to be in the child's *best interests*.[37]

However, this "definition" runs into significant difficulties in practice when interested adults disagree on the child's *best interests*, highlighting that there does not exist an agreed upon "hierarchy" of benefits and burdens relating to children. For example, how should the "benefit" of the prolongation of life be compared with the "burdens" of survival with ongoing medical problems? Should life be accorded a higher order importance – or should "quality of life" be given a higher value in making a determination of proportionality?

Moreover, the decisional agent is required to not impose his/her own views on the benefits and burdens involved for the child. Some empirical research has demonstrated that determinations of what is best for a child vary widely across adults involved in defining the interests of a child. For example, it has been reported that the quality of life for children

[37] For detailed articulations of *best interests*, see: AAP (1994; 1995); Alderson et al. (2006); CPS (2004); Harrison et al. (1997); Kenny et al. (1998); Kopelman (2010); Melton (1999); Miller (2010); Ross (1998; 2006); Sayeed (2010); Weir & Peters (1997).

living with disabilities is commonly under-appreciated by others, highlighting that adult decision-makers draw on a general negative bias toward disability, misrepresenting a child's actual "lived" balance of benefits and burdens.[38]

Other research has highlighted that socio-cultural context significantly shapes how *best interests* will be defined for an individual child. For example, in research examining decision-making processes for children regarding life-sustaining treatments in Quebec, France and Italy, it was clear that the parents and physicians all agree that treatment should be based on the child's *best interests*, yet there were major discrepancies in how this was construed (Carnevale & Bibeau, 2007;[39] Carnevale et al., 2007;[40] Carnevale et al., 2011;[41] Carnevale et al., 2012[42]). In Quebec, there was a primary recognition that this is defined largely in terms of what the parents think is best for the child,[43] whereas in France and Italy, physicians are considered the primary decisional agents. Although these French and Italian physicians should be engaging in an "objective" weighing of the relevant benefits and burdens for each child, it is remarkable that in the French context, physicians are

[38] For empirical demonstrations, see: Carnevale et al. (2006); Dickinson, Parkinson, Ravens-Sieberer, et al. (2007).
[39] Carnevale & Bibeau (2007) investigated (a) how life-support decisions are made for critically ill children in France; (b) the cultural context within which these decisional practices have arisen; and (c) the ethical implications of these practices. Data were obtained from consultations with relevant experts, relevant French medical guidelines, French print media, empirical research reports and related seminal publications.
[40] Carnevale, Canoui, Cremer, Farrell, Doussau, Seguin, Hubert, Leclerc, & Lacroix (2007) examined whether physicians or parents assume responsibility for treatment decisions for critically ill children in France and Quebec, as well as how this relates to subsequent parental experience. The qualitative study included 31 parents of critically ill children, as well as 9 physicians and 13 nurses who cared for their children.
[41] Carnevale, Benedetti, Bonaldi, Bravi, Trabucco, & Biban (2011) examined: (a) How life-sustaining treatment decisions are made for critically ill children in Italy; and (b) How these decisional processes are experienced by physicians, nurses and parents. Focus groups with 16 physicians and 26 nurses, and individual interviews with 9 parents were conducted.
[42] Carnevale, Farrell, Cremer, Canoui, Séguret, Gaudreault, de Bérail, Lacroix, Leclerc, & Hubert (2012) examined (a) how physicians and nurses in France and Quebec make decisions about life-sustaining therapies for critically ill children and (b) corresponding ethical challenges. A focus groups design was used, which included 21 physicians and 24 nurses (plus 9 physicians and 13 nurses from a prior secondary analysis).
[43] That is, in Quebec, *best interests* was defined largely in terms of what the parents thought was best for the child as long as the parents did not request unreasonable treatments. However, there was no agreed-upon understanding of how "unreasonable" should be defined in such a context.

significantly driven by the prevention of an outcome with significant disability. It is considered clearly preferable to withhold resuscitative treatments and allow a child to die rather than survive with major disabilities. On the other hand, in Italy, physicians are practicing in a setting where national norms have assigned a quasi-sacred value to life implicitly prohibiting the withdrawal of life-sustaining measures in such cases. In Italy, it appears that "quantity" of life is considered more important than "quality" of life, whereas in France – a neighbouring country with similar economic means to provide life-sustaining treatments – these values are generally reversed. In both cases, these determinations are claimed to be based on children's *best interests*. This distinction appears to be rooted in implicit underlying societal values and beliefs relating to the "sanctity" of life and the "quality" of life.[44]

In short, the *best interests* standard is the most widely accepted standard for medical treatment decisions for children, yet there is no accepted common definition and in practice it is construed highly diversely, reflecting underlying contextual values and beliefs that are commonly under-acknowledged. This problem may be rooted – at least partly – in Taylor's "moral malaises" of modernity (Taylor, 1989; 1991; 2007), where the collapse of prior religion-based moral orders has resulted in a vacuous or unspecified substantive moral ground that could help orient approaches to ethical dilemmas.

Best interests is supposed to protect children from remaining "means" that serve the "ends" of adults, so that children can be considered "ends" in their own right. However, this standard is largely defined in terms of values held by individual adult surrogate decision-makers, such that children's interests are commonly defined by what adults say is

[44] This will be examined in greater detail in the next chapter, in relation to Taylor's *horizons of significance* and SI.

best for the child – with some emerging research in disability studies indicating that these adult determinations of a child's interests are commonly discrepant from children's own "lived experiences".

Concluding Remark

The analysis undertaken in this chapter highlights that despite the tremendously important goals and accomplishments of the *best interests* standard, there remains a significant amount of work to be done in clarifying and articulating the conceptual and operational definition of this standard.

In the following chapter, I examine the issues highlighted in this chapter and the preceding chapter, in light of the Taylorian framework for this thesis. These are examined in relation to Taylor's key concepts and arguments relating to moral outlooks in the modern West.

Chapter 5: The Moral Malaises of Modern Pediatric Medicine

Introduction

In the preceding two chapters, I traced (a) the early and current history of pediatric medicine and (b) contemporary pediatric bioethics.[1] In my analysis, I have highlighted aspects of the *horizons of significance* and SI that appear to underlie the emergence of pediatric medicine as it has taken shape in current-day North America.

In this chapter, I relate this examination back to my earlier discussion of Taylor's analysis of modernity. I attempt to demonstrate that (a) contemporary pediatric medicine has been shaped according to the prevailing *horizons of significance* and SI of the current era and (b) that a re-interpretation of pediatric medicine in light of Taylor's work can foster an important illumination in our understanding of both modern pediatric medicine and the corresponding ethical frameworks that have been developed in this field. This examination will require re-articulations of ideas developed earlier in this thesis, to help retrieve related *horizons of significance* and SI as well as corresponding goods and *hypergoods*.

This analysis aims to justify a paradigmatic shift in pediatric ethics; a move to a hermeneutic pediatric ethics, which will be further developed in the next chapter.

[1] The terms "pediatric medicine" and "pediatric bioethics" overlap throughout this thesis. The former refers broadly to the medical body of knowledge and practices in pediatrics, which includes an ethical dimension whether or not this is explicitly articulated, in addition to the more commonly acknowledged biological, psychological and social aspects of child health. "Pediatric bioethics" commonly refers to the body of knowledge and practices of bioethicists relating to childhood concerns. However a great deal of pediatric bioethics is articulated within the body of knowledge and practices of pediatric medicine as well, and therefore does nor refer exclusively to the knowledge and practices of formally recognized bioethicists. Indeed, pediatric bioethics is predominantly practiced by pediatric HCP through their identification and recognition of various ethical concerns, and their responses to these in the research and normative literature as well as their clinical practice.

Understanding Modernity

Modernity has been commonly characterized as a narrative of progress resulting in: evolution of the fittest species; triumph out of pre-science ignorance and "Dark Ages" bestiality; and liberation from obligations to conform to prescribed religious norms. Against this backdrop of "progress", Taylor highlighted three principal malaises in modernity; the rise of (a) individualism, (b) instrumental reason, and (c) political atomism.

According to Taylor, the scientific revolution and secularization – which unfolded as inter-related parallel societal phenomena – were pivotal aspects of the horizonal shifts that characterize modernity. The pre-modern teleologically theistic order of the universe, which was oriented toward divinely defined ends, was displaced. This gave way to a new dominant order; a universe of mechanical objects whose properties could be revealed through (scientific) systematic observation and manipulation. This paradigmatic shift was initially centered on the physical sciences, but was then extended to the human sciences. Human life has come to be understood increasingly in light of "objective" scientific investigations.

The pre-modern order was also displaced by a modern order where human life is understood in terms of "atomistic instrumental individualism" (i.e., drawing on Taylor's three malaises). The modern self has come to be regarded as the ultimate arbiter for ascertaining truths, grounded in the "affirmation of ordinary life". Taylor has characterized this as an "inward turn" toward individually chosen goods (i.e., moral ends) and instrumentally effective means to fulfill them.

Although tremendous benefits have arisen from the narrative of "evolution, triumph, and liberation" of modernity, the modern era is also struggling with significant moral "angst", rooted in Taylor's moral malaises of modernity. For Taylor, modernity is

confronted with a crisis of meaning resulting from the prevailing ontology-less epistemology (i.e., the pursuit of truths without foundational moral grounds). The current moral order is vacuous, as there are no prevailing agreed-upon moral foundations, or *hypergood*, that can orient "the good life".

However, Taylor has also pointed out that the malaises of modernity are not a necessary consequence of the scientific revolution and secularization. Moreover, in his examination of SI, Taylor has also argued that although prior moral outlooks may be displaced by new dominant outlooks, earlier outlooks are not erased. Moral outlooks and their corresponding goods, *hypergoods*, *horizons of significance*, and SI persist in various ways and can be retrieved through hermeneutic analysis. This retrieval can foster a renewed understanding and help reconcile moral malaises – which Taylor undertakes throughout his analyses of modernity.

Re-articulating Modern Pediatric Medicine

In my examination of the emergence of modern pediatric medicine, I highlighted socio-historical research that demonstrates "childhood" is a social construction. In recent centuries, the initial years of life became distinguished as a distinctive phase of life. The ways in which childhood has been characterized has shifted over the years.

Extending Taylor's arguments, social constructions are inescapably rooted in SI – it would be "unimaginable" to construe phenomena outside of the SI of the corresponding (socio-historical) time and place. In other words, Taylor's work calls for a move beyond the identification of childhood as a social construction. Rather, the *imaginaries* underlying construals of childhood have to be (hermeneutically) elucidated, to advance our understanding of morally meaningful considerations relating to childhood. This retrieval

should be mindful of Taylor's view that multiple SI may co-exist, as the dominant SI may displace or conceal other SI.[2]

Children were initially "managed" within the private domain of families, regarded as a father's possession. States gradually became involved in childhood matters; initially to uphold paternal interests, which then shifted to regard for children as state interests, and eventual consideration of children as ends in themselves with their own interests.

Current-day pediatric medicine is predominantly centered on the *best interests* standard. "Good" pediatrics is essentially defined in terms of what serves the (dependent) child's *best interests*. Although current sociological analyses highlight a recent tension between regarding children as incapable, dependent, and vulnerable versus a consideration of children as capable agents (Lee, 2001), the former remains the clearly dominant social construction of children and childhood. This appears to have shaped the centering of pediatric medicine on the *best interests* standard – construing children as vulnerable and in need of protection.

The general social construal of children has unfolded alongside and in inter-relation with the relatively recent emergence and development of pediatric medicine in the 1900s. The latter should be understood within its corresponding context. Although the scientific revolution had already significantly displaced the primacy of religiously-grounded conceptions of the universe, this shift was further consolidated in the 1800s, through the

[2] Taylor's view that multiple SI may co-exist - that a dominant SI may displace or conceal other SI - poses a significant challenge for this investigation. In attempting to articulate a SI corresponding with the contemporary societal contexts of pediatric medicine, I am continually attempting to navigate a tension regarding terminology. In the context of modernity, there can be multiple SI that co-exist; one may be dominant and others may be concealed. However, there can also be a multiplicity of goods within particular societies – that may be contenders for *hypergood* status – which are embedded within multiple *imaginaries*. Should this be construed as a constellation of diverse SI, or a pluralistic SI within which there are diverse moral outlooks and goods? I eventually lean toward this latter view, of a "singular" pluralistic SI, for clarity of expression purposes and because it appears more congruent with Taylor's conception of SI. It appears plausible, however, to characterize such a societal context as a constellation of SI instead.

works of scientists such as Charles Darwin. This shift was extended to medicine in the early 1900s, as medicine gradually adopted science as its primary paradigm. Whereas the universe was previously considered under the ultimate control of a "divine order", scientific achievements were increasingly demonstrating ways in which "man" could control the universe.

Eugenics and social hygienics emerged as a science-based initiative to "improve" the population. Against this backdrop of the rise of science in medicine, emerged initiatives to diminish infant mortality. Interestingly, this was grounded in state-mediated population regulation; to improve the economic and military strength of Western nations. States turned to the growing power of science, more specifically scientific medicine, to control population health; which was previously considered outside of human control. This was further extended into the general "regulation" of children's health (i.e., beyond infant survival concerns), eventually into state monitoring and management of children's growth and development – largely through the control of mothers' parenting. These involved a constellation of shifts of authority: from women to men, from the private domain of the home to the professional domain of hospitals, from a family focus of control to an ultimate designation of authority within the state.

In the mid-1990s, against this backdrop of utilitarian state-mediated "concerns" toward child health, emerged a number of humanitarian-oriented initiatives to identify and protect the rights and interests of individuals; some of these specifically articulated standards for children. The *best interests* standard stood out for most matters relating to children, which was eventually explicitly developed within pediatric medical contexts, as bioethics was "born" in the third quarter of the 1900s.

By the end of the 1900s, pediatric bioethics (i.e., pediatric medical ethics) developed into the ethical orientation for the care of children in medicine that is currently dominant throughout North America. This is centered on the *best interests* standard, parental surrogate decision-making, and state oversight and intervention in cases where parents' upholding of children's *best interests* is questioned.

Re-articulating the Moral Malaises of Modern Pediatric Medicine

In the previous chapter, I highlighted three moral issues regarding contemporary pediatric medicine: (a) the convergence of law and ethics; (b) the construal of children as incapable and dependent; and (c) the ambiguous nature of *best interests*. In the following section, I argue that these three issues are rooted in the malaises of modernity identified by Taylor. I refer to them as the *moral malaises of modern pediatric medicine*.

These three malaises were identified in the light of Taylor's hermeneutical framework and his analysis of modernity. Although the identified malaises of modern pediatric bioethics are rooted in Taylor's three malaises of modernity, they do not correspond directly "one-to-one" with each other.

Convergence of Law and Ethics

The intersection of law and ethics in the development of an ethical framework in pediatric medicine is understandable; both fields are important normative sources. Some scholars have highlighted this interrelation as a potential problem for bioethics in general,

not only in pediatrics, as ethics can become conflated into law; shifting toward "legalistic" ethics.[3]

Ethical examinations of various medical concerns commonly entail an extensive review of related legislation and notable court judgments. These are thoroughly discussed in leading bioethics textbooks and education programs. However, given the significant social power of law and the authoritative impact of litigation on medicine, some scholars have pointed out a worry that bioethics can become defined by law – that bioethics can become a mere restatement of legal outlooks. For example, in pediatrics, child law requires that treatment decisions for children be based on the child's best interests, which is ordinarily determined by the parents as surrogate decision-makers for the child. As discussed in the previous chapter, this legal framework establishes a constellation of protections for children that previous history demonstrates are needed. The principal bioethical statements by the leading pediatric medical societies in North America are predominantly reiterations of the child law requirements for the care of children (e.g., AAP, 1994; 1995; CPS, 2004) – they construe pediatric bioethics almost identically and exclusively according to the standards of child health law.

Some literature has discussed the importance of the interrelation between law and ethics. Schneider (Schneider, 1994; 1996) outlined what he considered an optimal relationship between these fields. His arguments essentially assert that law is a necessary but not sufficient source for bioethics; recognizing legal standards is required for ethical medicine, but this does not nor should not completely define bioethics. For Schneider, law should be regarded as a minimalist ethics in medicine. Law stipulates what is minimally

[3] "Legalistic" is used here to convey a "law-like" conception of ethics; where ethics is construed quasi-identically as law. This concern has been examined thoroughly by Schneider (1994; 1996).

required for "good" medicine – bioethics should aim toward a higher ethical standard for medicine.

The *best interests* standard and surrogate decision-making do not adequately recognize the full scope of moral concerns involved in the care of children. The interests of parents, siblings, grand-parents, HCP, and other interested persons and organizations are regarded in law largely as potential conflicts of interests that the patient should be protected from. Conflict of interest is a potential problem for which law provides helpful requirements. However, these others also have "moral lives"; their lives are also morally meaningful. The growing shift toward *family centered care* calls on HCP in pediatrics to recognize the broader implications of a child's illness – the family is commonly considered as a focus of care (AAP, 2003). Pediatric clinicians form relationships with various members of the family – directly or indirectly. Parental wishes are considered important to pediatric HCP not only in terms of how these relate to the interests of the ill child. Rather, fostering a parent-HCP relationship is a moral end in itself – they are not developed solely as means to ascertain the patient's *best interests*. When a child dies, it is widely accepted within pediatrics that HCP need to provide some forms of continued attention to the grieving parents and siblings.[4] If in working with a particular family, the HCP learns that one of the siblings is unfavorably impacted by the condition of the ill child (e.g., sibling worries or stresses when the patient has cancer or severe burns, or when the sibling is stressed by the parents' reactions to the child-patient's illness), these sibling worries are commonly considered clinically relevant for the HCP professional caring for the ill child.

[4] Numerous papers in pediatric medicine have outlined how relational engagement for pediatric HCP with families is a "best practice" standard, including families with a dying or deceased child. For examples, see: Browning, Meyer, Truog, et al. (2007), Eggly & Meert (2011), Macdonald, Liben, Carnevale, et al. (2005), Meert & Eggly (2011), Meert, Schim, & Briller (2011), Meyer, Sellers, Browning, et al. (2009).

HCP relationships with a patient's family members have multiple dimensions – family members are not regarded as mere surrogate decision-makers. Over time, these relationships should become trustful and respectful, according to standards for good pediatric practice.[5]

There are additional moral concerns involved in the care of children that are inadequately recognized by the *best interests* standard and surrogate decision-making. For example, the viewpoints of young children are essentially discounted – their voice is attributed some recognition when their "level of maturity" demonstrates that they have "adult-like" decisional capacities. Although young children may understand and relate differently from adults to presenting ethical questions, there is a growing body of literature that demonstrates that they too have "moral lives"[6] – this is discussed further in the next malaise. Young children have a sense of right, good, and just, with corresponding experiences of moral outrage or comfort, although these can differ tremendously from moral outlooks among adults. The *best interests* standard essentially trumps children's perspectives as ethically "immature" – "protecting" them from their decisional incapacities; particularly discounting the ethical significance of young children's perspectives.

In another example, contemporary pediatric medicine frequently gives rise to very difficult situations, where the child's *best interests* appear virtually impossible to ascertain. This is in part related to the ambiguous nature of *best interests*, which is examined directly in the third malaise. Sometimes this problem relates to situations that present genuinely "tragic" dilemmas; cases where all available options are significantly unfavorable, such as

[5] As described by the American Academy of Pediatrics (AAP, 2003).
[6] As stated in chapter 4, this includes empirical research (Bluebond-Langner, 1978; McPherson, 2007), reflective clinical analyses (Coles, 1986; Sourkes, 1995), review statements (Harrison et al., 1997; Kenny et al., 1998), theoretical/normative articulations (Alderson, et al., 2006; Kagan & Lamb, 1987; Ross, 1998; 2006; Weir & Peters, 1997), and court testimonials (Melton, 1999).

death or survival with severe disability. Neither of these outcomes would be commonly regarded as a child's interest. Such scenarios force choices between "bad" alternatives and commonly lead to significant moral residue, despite attempts to act responsibly and attentive to the child's interests.[7]

In the context of a Jehovah's Witness family, whose child has hemorrhagic shock, a different form of tragedy emerges. When a blood transfusion is deemed the only means to preserve the child's vital functions – otherwise the child would die – the parents are asked to consent to a treatment that for them entails a profound spiritual violation. They are torn between committing a morally horrendous act or losing the life of their child. This is a tragic dilemma that is commonly under-recognized, when prevalent pediatric bioethics discourse construes this as a dilemma between recognizing the parents' right to religious freedom and to determine which medical treatments their child should receive "versus" the child's right to life and to have his/her *best interests* upheld. This "rights-based" dilemma construal discounts the profound ethical quandary encountered by parents, as well as the significant difficulties this poses for HCP, who have to either "side" with the parents' religion-based preferences or the child's right to life. Indeed, it is quite common for these parents to emphatically request from HCP that they withhold blood products while also requesting that they save their child's life. The *best interests* standard addresses only a very narrow dimension of the complex moral phenomena involved in such cases.

Although bioethics has proposed a number of ethical frameworks for understanding medical contexts beyond law-centered approaches, such as feminist, narrative, hermeneutics, casuistry, virtue ethics, among others, these remain largely "peripheral"

[7] For an in-depth discussion of moral residue in the context of pediatrics, see Austin and associates (2009) for their examination of *moral distress* and Carnevale (2007) for a review of moral residue relating to *tragedy* in pediatric critical care.

within pediatric bioethics.[8] The pediatric bioethics literature is predominantly centered on specifying legalistic applications of the *best interests* standard; i.e., how should this be defined and by whom in various types of clinical scenarios. It would appear that the recommendations of a child lawyer and a pediatric bioethicist would be similar in the most commonly identified cases. Indeed, this apparent conflation of law and ethics affects not only how identified concerns would be examined, but this shapes the actual concern-identification process, such that ethical phenomena are understood primarily when they seem to entail problems in the application of the accepted legal standards. The concerns described above regarding family interests, perspectives of young children, or tragic choices, are uncommonly highlighted as ethical problems.

This "ethics and law conflation" phenomenon corresponds with Taylor's critique of modern moral theory. As described in an earlier chapter, Taylor has highlighted that the dominant epistemology of Western modernity has shifted toward an instrumental proceduralist moral orientation, suppressing the moral ontology underlying conceptions of human life (Taylor, 1989; 2003). The moral malaises of modernity have resulted from the ongoing suppression of this moral ontology (Taylor, 1991). Suppressing the view that moral life is oriented toward ultimate (substantive) goods, proceduralist ethics can be centered on rational calculative thinking about moral problems – rooted in the modern Western primacy of instrumental reason, without appeal to a substantive moral ground (Taylor, 1991).[9] When a "moral ground" is specified within this proceduralist outlook, this

[8] This problem has also been described for bioethics in general, not just in pediatrics. For further discussions, see: DuBose, et al. (1994); Fox (1990; 1994; 1996); *Kennedy Institute of Ethics Journal* (1995); Kleinman (1993); Weisz (1990).

[9] Taylor refers to a form of proceduralism that can be contrasted from other moral ontological outlooks that can resemble proceduralism, such as utilitarianism, for example. Utilitarianism can in practice appear like an exclusively proceduralist ethical outlook, yet it is clearly centered on substantive moral grounds such as "utility" or the "greatest happiness principle".

is typically limited to principles of justice – including procedural principles – without explicit regard for the foundational moral values that may underlie them. Taylor criticizes this outlook for unaddressed questions, such as "Why should one be moral?". Proceduralist ethics cannot adequately address these types of underlying moral questions because they require an articulation of the ultimate good or right that moral agents seek to orient themselves toward; i.e., a background *horizon of significance* and corresponding SI. A society's *horizon of significance* serves as its moral framework for discerning "the good" through *qualitative distinctions* – identifying which actions or modes of life are incomparably higher - in light of local *distinctions of worth* and the process of *strong evaluation* (Taylor, 1989). The *hypergood* stands out among the incomparable goods, as the most important standpoint from which all other goods are judged (Taylor, 1989) – superseding all prior *hypergoods* as well as all other contemporary goods.

The prevalence of "legalism" in bioethics,[10] corresponds with the dominant moral proceduralism of modernity described by Taylor. In the context of adult bioethics, significant weight is accorded to the patient's choice, rooted in the doctrine of informed consent.[11] An adult patient can refuse any treatment for any reason, as long as they demonstrate decision-making capacity.[12] For example, if an adult patient states that he/she wishes to die, for example seeks physician-assisted suicide for an end-stage condition and states that he/she would otherwise commit suicide; although the patient's mental capacity would be assessed, everyday medical ethical models do not commonly recognize the full range of moral concerns underlying such a situation beyond decision-making capacity and

[10] That is, the elaboration of bioethical orientations that appear identical to approaches in law (Schneider, 1994; 1996).
[11] It should however be highlighted that this has resulted in important contributions to the ethical enrichment of modern medicine.
[12] For example, in *Malette c. Shulman* (1990), the court ruled that a capable adult can even refuse blood products required to save his/her life.

that the active ending of life with medical means is legally prohibited. This is illustrated in the following case example.

On Friday, January 28, 2005, a 78-year-old Ottawa-area man committed suicide, as he had publicly announced he would (Sorensen, 2005). Marcel Tremblay announced on the Canadian media that he planned to kill himself with a helium-filled bag over his head because he suffered from pulmonary fibrosis, an incurable lung disease that made it difficult for him to breathe. He wished to stimulate a national debate on assisted-suicide. When he initially announced his intentions, he underwent a psychiatric evaluation, which determined that he was mentally capable. His lawyer stated that the police was "satisfied" that he did not have any mental problems – adding that the police were in no position to stop what in Canada is a legal act because committing suicide and attempting to commit suicide were decriminalized in 1972 (Sorensen, 2005).

This man had at least two formal engagements with medicine: (a) a respiratory medicine specialist managing his primary medical problem and (b) the psychiatrist who evaluated his mental capacity. Despite this significant medical involvement, this ethically complex case was ultimately framed as a quandary between the patient's wish for assisted-suicide, the risk of committing "mentally incapable" suicide, and the current legal prohibition of assisted-suicide in Canada – essentially the legal questions relating to the case. Absent from this discourse were explicit considerations of questions such as: what value should be accorded to human life; how can we understand a moral order that presents such difficult medical conditions that result in profound suffering; how can suffering be understood and comforted in such situations; is the elimination of suffering even through the ending of life a greater "moral imperative" than "living with suffering"; and how should medicine be involved in these moral matters? Despite these readily apparent moral

concerns, among many others that can be envisaged, the prevalent questions that emerged related to procedures that needed to be followed and the standards the procedures should apply. That is, a man seeks assistance for committing suicide. This is directly linked with widely applied "signaling" procedures in medicine that require a mental capacity evaluation: the procedure was to activate the public emergency security system (i.e., police and ambulance) to initially restrain the person from committing such an act, in order to perform an evaluation based on the standard of mental capacity. In fact, when the mental capacity evaluation was completed, the man was released from the hospital, but had to find his own means to return home – after he had been involuntarily apprehended and transported from his home in the first place.

Proceduralism is commonplace in pediatric medicine as well. As described above, a common ethical problem in pediatrics is when parents are Jehovah's Witnesses and refuse medically required blood products. The common response model is to seek court authorization to administer blood products against the parents' objections, which courts will usually grant.[13] The ethical problem is commonly framed exclusively in terms of legal procedures and authorizations that need to be followed. The wide range of underlying moral concerns generally remains concealed.

As is common in bioethical approaches in general, pediatric bioethics has "evolved" predominantly as a legalistic deontological framework of surrogate decision-making based on the *best interests* standard. The dominant contemporary moral outlooks do not relate to

[13] For examples of courts granting authorization to administer blood products against parental wishes, see: *A.C. v. Manitoba*, 2009 as well as *B.(R.) v. Children's Aid Society of Metropolitan Toronto*, 1995. Moreover, Ridgway's (2004) analysis of American court judgments has demonstrated that across a wide range of presenting pediatric cases, courts rule most commonly in favor of physicians rather than parents.

clearly-recognized substantive value grounds.[14] I argue below that this in turn obscures understandings of *best interests.* Consequently, pediatric bioethics systematically turns to legal procedures to determine which agent is the ultimate legal authority for each case – leaving it to that agent to then attempt to individually define *best interests* for the presenting case.

Child as Incapable and Dependent

As described earlier, principlism is a dominant ethical framework in contemporary medicine, within which *respect for autonomy* is a central hallmark of modern bioethics. In practice, this is operationalized through the doctrine of informed consent. The ethical permissibility of medical care is largely defined by what the patient accepts or rejects. For example, the prevailing ethical view is that medical care should respect the wishes of a patient, even if the patient rejects interventions required to preserve his/her life (e.g., blood transfusions), out of respect for the patient's autonomy. Adults are presumed to be self-determining agents with the capacity to independently judge the moral means and ends of their lives.

This corresponds with Taylor's examination of modernity, where the prevalent SI is centered on individualism; giving rise to a *horizon of significance* centered on an atomistic independent self as a form of *hypergood*;[15] a self that is considered capable and interested in autonomously shaping his/her moral life.

[14] Although some bioethical frameworks have been developed with an explicitly developed moral "grounding" (e.g., virtue ethics, prominently articulated by Edmund Pellegrino - see: Pellegrino & Thomasma, 1981; Pellegrino, 1995), these are largely "peripheral" within pediatric bioethics, as stated earlier.
[15] The terms "atomistic" and "independent" are not synonymous in Taylor's analysis of modernity. These terms are described and discussed in detail earlier in chapter 1.

Against this moral ideal of the autonomous independent self, has emerged the modern understandings of childhood as incapable and dependent, and therefore vulnerable. This dependency has been framed through various custodial relationships; predominantly with their parents and/or various state bodies. Over time, the valued aims of child development shifted from a state-centered contribution to economic and military interests to a child-centered actualization of the child's *best interests*. Throughout these shifts, children have been construed predominantly as dependent.

"Human beings" and *"human becomings".*

Socio-historical analyses have highlighted how *childhood* has been *constructed* as a social category.[16] Ariès (1962) has argued that prior to the sixteenth century in Europe, there was no conception of childhood as distinct from adulthood. With the emergence of wealthy Europeans, emerged the "coddling" of children. Children became seen as a source of delight for adults through their clumsiness and incompetence. Children's apparent helplessness, seemed to also warrant their receiving greater love and attention (Ariès, 1962).

There appeared to be an ontological shift, as childhood was constructed as a new social category. Childhood has subsequently undergone various transformations, in line with corresponding societal contexts. The social distinction between childhood and adulthood, on the basis of chronological age, has served as a justification for the social distribution of rights, responsibilities, dignity, and respect. Lee (2001) has characterized the

[16] For a historical examination of children with a political philosophy framework, Renaut (2002) has analysed complex questions regarding rights, obligations, and responsibilities regarding children, and how these have unfolded over time. In *Nos idées sur l'enfance*, Dupeyron (2010) has examined Western conceptions of childhood, with a particular focus on education. He highlighted that despite the recent recognition of children as subjects with rights, they remain highly dominated in the social structures that they live within.

social distinction between adults and children in modernity as "human beings" and "human becomings". Lee's distinction is described below in some detail, because it provides a strong integration of the wide body of socio-historical studies of childhood analyzed for this thesis.[17]

Adults have become construed as "human beings", capable of independent thought and action; personal independence serves as the basis for according respect to adult persons. In contrast, children have become construed as "human becomings", regarded as changeable, incomplete, lacking in self-possession and self-control. In short, adults are seen as complete and independent, while children are incomplete and dependent (Lee, 2001).

The rise of this distinction has been related to early to middle twentieth century social processes and structures that shaped social roles and practices, along with corresponding attributions of responsibility, authority, and obligations (Lee, 2001). Toward the end of the twentieth century, the social contexts that gave rise to these social distinctions between adulthood and childhood were transformed, creating tensions and erosions in systems that upheld these distinctions.

Earlier in twentieth century North America, the overarching norm that defined social roles was based on a model of adult maturity defined predominantly by occupational and personal-relationship stability (Lee, 2001). This was regarded as the grounding for personal autonomy and "completeness". The initial stage of life (i.e., childhood) was defined by its contrast with this construal of adulthood. Childhood was seen as a gradual

[17] The principal works examined in this particular historical analysis of childhood included: Ariès, 1962; Comacchio, et al., 2008; De Mause, 1976; De Singly, 2004; Heimer & Staffen, 1998; James & Prout, 1997; James, et al., 1998; Lee, 2001; Mayall, 1996; 2002; Prout, 2000; Qvortrup, 2005; Walvin, 1982; Wright, 1988. Additional historical and sociological sources were reviewed throughout this investigation and are cited accordingly.

building toward stability and independence. Children's corresponding instability, incompleteness, and dependence served as a rationale for discounting children's voices.

In this historical era, adulthood was commonly characterized by permanent jobs and permanent intimate relationships. In North America, this view of adulthood has been linked to "Fordism" (Lee, 2001). "Fordist" national economies and patterns of work were described by Harvey (1989) as post-WWII (i.e., 1945 to early 1970s) phenomena. The Ford Motor Company created an employment and work model that significantly impacted the North American labor context, as well as public and private social systems; including family life. Ford developed mass production assembly lines that claimed to enhance cost-effectiveness through standardized manual labor. Moreover, stable employment conditions were created to ensure a stable and competent workforce that could maintain productivity in line with rising market demands. Workers' skills remained narrow and fixed throughout much of one's employment.

The significant capital growth of the time led to ongoing investment in factories and stable employment until retirement for its workers. Employees' lives were therefore stable financially and geographically (i.e., relocation was not required). Stability became a "total way of life" for industry, workers, and government bodies, based on continuing economic growth. Employee wages were strong and consistent, and consumer purchasing was stable. Employee experience and expertise were valued. Staff developed company loyalty. Employment geographical stability was commonplace; i.e., once an employee was settled into a job, relocation was never required for employment stability or even advancement.

This picture of a stable adulthood as a worker was mirrored in the private sphere of family life, as long-term intimate relationships (e.g., permanent marriages) were commonplace. This was described by Talcott Parsons (1971) as the "Normal American

family". This was characterized by: a monogamous marriage between a man and a woman until one died; a married couple that lived together, shared income and raised children together. The family was seen as a stable context to accommodate the instability and incompleteness of growing children. Family roles were clearly defined and stable; gender roles were fixed. As a site for the socialization of children, the family reproduced societal institutions and patterns.

The twentieth century Fordist conception of children drew on the seventeenth to nineteenth century rise of military and economic competition through colonization. During this time, childhood was increasingly seen as a site of investment for the future. Drawing on a "gamekeeper" metaphor, children were "raised" to ensure their optimal "cultivation". Schooling and "educated mothering" were actively promoted to ensure children's development (Bauman, 1987; Donzelot, 1979).

The modern model of stability and independence to characterize adulthood became the basis for attributing rights and recognition, as well as power and authority to adults. In turn, this model served to justify the withholding of rights, recognition, power, and authority from children because of their instability and incompleteness (Lee, 2001).

Chronological age served as a form of social "cloak of invisibility" – adults were presumed stable and complete and therefore meritorious of the social privileges associated with adulthood, as individual adults' personal limitations were commonly concealed.

It is noteworthy that while it is currently widely argued that age is a justified criterion for determining how social roles – and corresponding opportunities - should be shaped, gender and race were once also agreed-upon criteria for social structuring. The societal context underlying social structuring - i.e., SI – can help uncover the social

processes that shape the construction of various social roles. Sometimes, these processes are discriminatory.

As the twentieth century unfolded, Fordism confronted significant problems. In the late 1960s, domestic markets became saturated, which triggered a shift to more competitive global markets, lower wages, and consequently, less employment stability (Lee, 2001). During the 1970s and 1980s, Fordism declined in western economies. Stability became viewed as "rigid", as "flexibility" became more valued. In practice, this resulted in employment on demand, flexible manufacturing, and decreased employment loyalty. The "flexible new economy" required *changeable* geographical location, employment status, range of skills, and self-identity. Additional social shifts resulted in changes in the previously stable intimate life, such as birth control, more visible gay and lesbian relationships, and feminism.

The late twentieth and early twenty-first centuries became an "age of uncertainty"; adulthood is no longer a state of stable completion and childhood is increasingly open to redefinition. Adult life has been substantively transformed: permanent jobs and permanent relationships are less common. Adults no longer consistently measure up to the prior image of a standard adult. Some sociologists of childhood have highlighted that the justification for maintaining the human beings/becomings distinction between adults and children has collapsed, arguing that the social category of "human becoming" should be emptied and abandoned (Lee, 2001). Children should be seen as "beings" alongside adults, rather than "becomings"; deserving of respect and recognition.

Indeed, several forms of empirical research demonstrate that there are some fundamental flaws in the premises underlying the human being/becoming distinction. Whereas early human development psychological research upheld the dominant view of

human development as a trajectory from childhood dependence to adulthood independence (highlighting gender differences in this trajectory), subsequent research has pointed out ideological and sexist pre-suppositions underlying this early research. The ideal of autonomy as a universal striving for human development has been argued by some (Gilligan, 1982; Shweder, Mahapatra, & Miller, 1987) as an *a priori* philosophical bias perpetuated by early researchers, such as Erikson, Kohlberg, Piaget, and Levinson (Erikson, 1950; Kohlberg, 1981; Kohlberg, Levine, & Hewer, 1983; Piaget, 1932/1965; Levinson, 1978), which has distorted research design and theoretical development.

Feminist and cultural critiques of this research has highlighted that humans do not universally strive primordially toward independence; that interdependence is also highly valued (Gilligan, 1982; Shweder et al., 1987). Reliance on others is commonplace and highly regarded even among adults. Moreover, a growing body of research evidence is demonstrating that children are actually much more capable of engaging in moral deliberation and demonstrating "adult-like" ethical thinking and conduct (Bluebond-Langner, 1978; Coles, 1986; Sourkes, 1995). Children can quite commonly assume responsibility for their educational activities or the care of their medical condition, without compromising their interests. In fact, it has been argued that children can better achieve their own *best interests* in some domains of life when they are allowed to do so (McPherson, 2007; Melton, 1999; Schneider, Bersoff, & Podolsky, 1989). In short, the justifications for maintaining the human being/becoming distinctions do appear to be collapsing.

Taylor has argued that over time SI are not necessarily erased; they can be displaced or concealed by emerging dominant SI. In reviewing the historical "evolution" of childhood described above, we note that: (a) childhood has been predominantly construed in terms of

dependence; (b) there have been historical shifts regarding the prime agent of authority over children's dependence, primarily between the state and parents; (c) in early times, children were regarded as forms of paternal property and/or economic and military state investments; (d) the prevailing current view is that children are incapable and dependent and in need of protection, which should be managed in terms of promoting their *best interests*; and (e) there is an emerging understanding that children are capable of a much greater degree of independence than commonly recognized. These points highlight shifts between state and parental authority over children - with the recent consideration of the child as his/her own authority - as well as shifts in the substantive moral grounds underlying this authority, between other-centered (i.e., parent or state interests) and child-centered (i.e., *best interests*) frameworks.

These numerous and highly-diverse orientations have emerged and receded within relatively short timeframes. It would seem warranted to characterize the present-day SI as a constellation of these diverse outlooks, some of which are more foregrounded or visible, while others are concealed.

Our current SI is espoused to be centered on the *best interests* standard, with parents recognized as the usual decisional agents. Yet, the recurrence of cases involving children of Jehovah's Witnesses where court authorizations are sought to override parental authority, or cases such as Kandice (i.e., at the beginning of the thesis) where parents and HCP disagree over how to define the child's best interests and how state resources should be used, and the emergence of empirical evidence highlighting that children are commonly capable and wishing to be more responsible for decisions affecting them, demonstrates that our current SI does not consist of one sole *horizon of significance* or one *hypergood*.

The SI of modern pediatric medicine appears "pluralistic", consisting of a diversity of moral outlooks that co-exist; sometimes unproblematically, sometimes conflictually. The current SI recognizes multiple voices of authority in matters regarding children: parents, HCP, other state agents, and to some degree, children themselves.

Moreover, as the next section will highlight, the resolution of problems has to rely on a substantively undefined concept: *best interests*. When there is no agreement on how to operationally define this central ethical standard, the understandable clash that can result among the various authoritative agents will then turn to the dominant source for moral solutions: proceduralist courts (as described in the previous section). It can be recognized that this context can give rise to significant moral malaise, as many medical situations cannot readily accommodate a diverse set of, sometimes incommensurate, goods and forms of *hypergoods*. This complexity is further amplified in the next section when the diverse conceptions of *hypergoods* associated with understandings of *best interests* come into play.

The Ambiguous Nature of *Best Interests*

I described above the common scenario that arises in pediatric centers when a child's medical condition requires a blood transfusion and the parents are Jehovah's Witnesses. Such a scenario can be contrasted with another common scenario, the one presented in the case of Kandice at the beginning of this thesis; i.e., the case of an infant with a degenerative brain disease where the treating physicians were planning to withdraw life-sustaining mechanical ventilation while the mother demanded that these measures be maintained. In both cases, all parties argue that their treatment decision is based on the child's *best interests*. In one case, the parents favored maintaining life-sustaining treatments and in the other they refused such treatment, while the treating physicians opposed the

parents' views in both scenarios. Each agent defined the child's *best interests* differently in each scenario. Moreover, one scenario explicitly involves religious views and the other does not.

Earlier in this thesis, I outlined findings from pediatric critical care research in France and Italy. This comparison highlighted that in France it is commonly held that children's *best interests* entail the prevention of significant disability; that medical treatments should be withheld or withdrawn even if the result would be death, in order to prevent severe disability as an outcome (Carnevale et al., 2007). Until the recent past, some cases of this kind in France were "solved" through active euthanasia, even though this was not legally permitted.[18] In contrast, in Italy, it is currently the prevalent norm that once resuscitative interventions have been initiated, these cannot be withdrawn – that this would be tantamount to active killing (Carnevale et al., 2011).

Two very different views exist in France and Italy on the ethical permissibility of withdrawing life-sustaining interventions; in both contexts, these positions are argued in terms of the child's *best interests*. In France, it is argued that children have an interest to avoid life with disability even if this entails their death, whereas in Italy it is held that children have an interest in living as long a life as possible, even if this is sustained through prolonged resuscitative technologies. This contrast highlights two sharply distinctive forms of *hypergoods*: able-bodied-ness in France (commonly referred to as "quality of life") and "sanctity of life" in Italy. This does not mean that each societal setting does not value both goods. Rather, we have a clear indication that, in each of these countries, one good is clearly regarded on a higher ground; as a form of *hypergood*.

[18] See note in chapter 4 that outlines Oriot's examination of French neonatal practices relating to the "screening" for "handicapped" newborns and active termination of life through "arrêt de vie" (Oriot, 2008a; 2008b; 2008c).

Formal attempts to define *best interests* generally construe the concept as the decisional option that will provide the greatest proportion of benefits in relation to burdens, among available treatment options. It is implied that the surrogate decision-maker will "objectively" weigh the benefits and burdens relevant for the child in question; objectivity here requires that the decision-maker will not impose his/her own benefit/burden preferences.[19]

Within the prevalent conceptions of the *best interests* standard, two of Taylor's "malaises of modernity" are readily apparent and the third is implied. *Best interests* are to be judged exclusively in terms of the child's interests, without interference from potentially conflicting interests of others. Given the vulnerabilities inherent in children's dependence on others, it is presumed that surrogate decision-makers can have conflicts of interests between their own interests and those of the child that they are deciding for. *Best interests* requires a disengagement of these personal interests, to ensure that the child's interests are centered. The *best interests* standard implies an individualist conception of childhood.[20] Despite a child's dependence on others and his/her non-autonomy, the child is still formally recognized as a sole moral entity, in both legal and ethical terms.

Moreover, the child's interests are to be judged through an objective weighing of relevant benefits and burdens, through a form of calculative analysis that resembles Taylor's *instrumental reason*. This conception of "surrogate agency" presumes – in fact

[19] Indeed, it is generally held that HCP are to be "value-neutral" in their assessment of *best interests*. This is problematic in light of the comparative France-Italy research discussed above, as HCP inescapably rely on moral outlooks drawn against commonly concealed or unarticulated *horizons of significance* and SI.
[20] Although Taylor has highlighted concerns that can result from moral individualism, I acknowledge – as does Taylor – that moral individualism can also foster significant "moral goods"; e.g., by asserting that all human beings are distinct entities that have equal worth and dignity.

requires – a disengaged moral orientation.[21] Substituted judgment (i.e., for previously capable adult patients who have become incapable) requires that the surrogate decision-maker decides as the patient would have decided, which is premised on the surrogate having had some meaningful relationship and/or communication with the patient to understand the latter's outlooks on "the good life" for him/her. The *best interests* standard presumes that the patient in question has not been in a position to previously express a formally recognized statement of moral values and preferences, such as the way children are construed legally in North America. The surrogate decision-maker, who is usually the child's parent but sometimes can be a youth protection agent or a judge, is to appeal to unspecified "goods and harms" (i.e., benefits and burdens) and weigh these objectively for the individual child (Buchanan & Brock, 1990).

Nussbaum has highlighted the moral consequences and outright impracticability of such a disengaged objectivist operationalization of moral considerations, which applies directly to determinations of *best interests* (Nussbaum, 2000). An assessment of benefits and burdens relating to important decisions (e.g., medical treatment) would necessarily involve a deeper understanding of how these benefits and burdens are morally meaningful, for the "interested" person (i.e., the patient), other interested persons, and the broader community. What is the value of a human life? What is the value of a disabled human life? What does significant illness in a child require from those around the child? What is the significance of suffering? Should suffering be prevented at all financial costs? Should suffering be prevented at all human costs, even at the cost of shortening life? How do

[21] In a hermeneutical empirical study of family members' surrogate decision-making experiences, Chambers-Evans and Carnevale (2005) reported that it was highly problematic for these decision-makers to distinguish their own wishes and preferences regarding the patient's treatment from what might be "independently considered" best for the patient or what the patient might have wanted for him/herself.

"benefits and burdens" matter to a child? (e.g., prolongation of life, survival with disability, pain, suffering, permanent institutionalization) How should this "mattering" affect *best interests* assessments?

It should also be noted that empirical research has highlighted that surrogate decision-makers for children "impose" a significant anti-disability pre-judgment on their assessment of whether a disabled child's life should be sustained. It appears clearly impracticable to make such decisions "objectively".[22]

Indeed, the difficulties inherent in "applying" the *best interests* standard highlight a fundamental concern that Taylor has raised for modernity: the concealment of foundational moral grounds. The rise of science and secularization in modernity displaced the previously dominant theologically-oriented SI, resulting in an apparently vacuous foundational moral ground. The SI of modernity is not considered anchored in any agreed-upon *horizon of significance* or *hypergood* – there is no clear substantive good toward which "the good life" can be oriented.

For Taylor, this has led to a centering on the modern conception of selfhood, where what matters (morally) has become defined according to that which an individualized, instrumentally reasoning, atomistic agent chooses. This is the moral groundwork upon which bioethics has centered on respect for autonomy as a form of *hypergood*. However, autonomy fails as a *hypergood* because it is not inherently morally substantive; respect for

[22] Despite common assumptions that physical disabilities directly compromise quality of life, Dickinson and colleagues (2007) demonstrated in a study of 818 children with cerebral palsy in six European countries, that they had a similar quality of life as children in the general population in all domains except schooling, in which evidence was equivocal, and physical wellbeing, in which comparison was not possible. Additionally, in a theme issue of *Current Problems in Pediatric and Adolescent Health Care* (2001), the empirical research literature along with personal narratives by parents, grandparents, and physicians about caring for a child with a life-threatening condition were examined to demonstrate that statements regarding "quality of life" incorporate value judgments that are commonly under-acknowledged. It is argued that this is particularly problematic because these subjective judgments are used to deny access to medical care or withhold or withdraw life-sustaining treatments for some children.

autonomy is a legal and ethical principle but its moral grounding is vacuous in the ways it is commonly construed in everyday clinical medicine – as demonstrated in the clinical examples described in this thesis. For example, an initial understanding of respect for autonomy might imply that this is a *hypergood*. Yet, when an autonomous adult requests euthanasia or assisted suicide in North America, this is widely denied.[23] Human life is also an important good, which trumps autonomy when it comes to requests for assisted suicide, but is secondary when it comes to medical treatment decisions in the context of terminal illness; i.e., it is permissible not to prolong life medically in some situations. It can possibly be argued that autonomy is a quasi-*hypergood*, given the growing interest and support for the decriminalization of assisted-suicide. Yet, to this day, there remains a significant opposition to this decriminalization; and in recent years the Canadian Supreme Court rejected Sue Rodriguez's request for assisted-suicide, albeit with a narrow majority of 5 to 4 (*Rodriguez v. British Columbia*, 1993).

The tension between autonomy and sanctity of life is one among many other goods competing for *hypergood* status in North America. In the Canadian context of multiculturalism and respect for diversity, medicine is to consider making "reasonable accommodations" when possible.[24] For example, when a legally capable adult patient refuses a medically-required blood transfusion, this is generally accommodated, even if the

[23] With the exception of three American states that permit assisted-suicide (i.e., Oregon, Washingon, Montana).

[24] "Reasonable Accommodation" is examined in Taylor's collaboration with Maclure titled *Laïcité et liberté de conscience* (Maclure & Taylor, 2010). This was developed from the authors' work on the *Consultation Commission on Accommodation Practices Related to Cultural Differences*, which Taylor co-chaired with Gérard Bouchard in Quebec, Canada. (Bouchard-Taylor Commission, 2008; Final report was published in 2008: http://www.accommodements.qc.ca/index-en.html). This book extends the Commission Report chapter on *laïcité*; a term that refers to a French form of secularism, which took shape in nineteenth century France and was formally articulated in the 1905 French law on the separation of church and state (Acomb, 1941). Maclure and Taylor undertake a more advanced philosophical investigation of this notion than was possible in the Commission Report, examining *laïcité* in relation to liberal democracy.

consequence is death. It is noteworthy that in this case autonomous choice can trump the preservation of life, but not when the autonomous choice seeks assisted-suicide. However, in the context of pediatrics, although the accommodation of religious and cultural diversity is also required, a child's right to life would ordinarily trump the parents' choice to reject required life-sustaining blood-products.

In short, we do not have an agreed-upon *hypergood* to orient pediatric medicine. *Best interests* appears to circulate as a *hypergood*, but it lacks substantive moral content; there is no agreed-upon definition and it is common for engaged agents to construe a specific child's *best interests* in very diverse ways.

As Taylor has pointed out, the absence of a substantive moral ground in modernity corresponds with a turn to proceduralism. In pediatric bioethics, as there is no substantive definition of *best interests*, it is commonly operationalized in terms of how the authorized surrogate decision-maker chooses to define it for a specific child. Other interested adults can question the surrogate's interpretation of the child's *best interests*, although this challenge would have to rely on a "rival" construal of *best interests* for the child in question. If these disagreements cannot be settled, then the agreed-upon ultimate "moral authority" in pediatric medicine is a court – the court's determination of a child's *best interests* is then the recognized societal operationalization of the child's *best interests*.[25]

Best interests is commonly defined by what the surrogate (i.e., typically the parent) says it is. If there is a challenge, questioning, or disagreement regarding a child's *best interests*, then it needs to be ensured that the surrogate is following the formal requirements

[25] The court would also have to rely on substantively undefined *best interests*.

for the standard[26] and if the disagreement is not resolved then a youth protection agent or a court can intervene and assume authority. Then, *best interests* is defined by what these agents say it is.

In the end, *best interests* is defined by whoever is procedurally authorized to make that determination, without appeal to any agreed-upon substantive moral grounds.

The Dominant *Social Imaginary* of Modern Pediatric Medicine: Summary Statement

The dominant SI within which children are understood medically can be articulated by integrating the moral malaises of modern pediatric medicine discussed above.

The congruence and apparent conflation of ethics and law results in a substantively vacuous moral proceduralism; where the ethical realm of pediatric medicine is predominantly defined and practiced according to the procedures of law. These procedures claim to rely on a substantive standard: *best interests*. But, the absence of an agreed-upon *hypergood* or set of goods to help define the moral content of *best interests* results in a circular proceduralism where this standard is defined by the agent designated by legal procedure. If this agent's determination is questioned, then legal procedure designates a subsequent agent, and so on until a court may be required to act as an ultimate authority, also without a substantive ground to appeal to.

The dominant conception of children as incapable and dependent is derived from the social distinction between adulthood and childhood. This is based on an ideal of adulthood centered on an individualistic, instrumentally reasonable conception of the modern self. This ideal serves as the basis for construing children as dependent and

[26] That is, that treatment decisions are clearly centered on the child's *best interests* and not the interests of others.

incapable, and therefore in need of adult protection. This protection was initially construed in state utilitarian terms, oriented toward state interests, but has shifted predominantly to a child-centered *best interests* standard. Although children are considered incapable and therefore restricted from access to a number of the entitlements of adulthood, they are considered worthy through their potential to become "human beings" in the future.

Political Atomism in Modern Pediatric Medicine

Taylor has argued that the first two malaises of modernity – individualism and instrumental reason – have given rise to a third malaise: political atomism (Taylor, 1991). For Taylor, political atomism implies an affirmation of the primacy of individual rights. This political viewpoint is centered on the attribution of certain rights to individuals, without significant regard for obligations to community or society. Society is regarded merely in instrumental terms as a *means* for fulfilling individual *ends*. Taylor has argued against atomism in favor of the Aristotelian view that "Man is a social animal, indeed a political animal, because he is not self-sufficient alone, and in an important sense is not self-sufficient outside a polis" (Taylor 1985e, 189).[27] Taylor argues for a politically engaged conception of human agency, where persons are concerned about the welfare of others both as an end in itself as well as for ensuring one's own flourishing. Indeed, Taylor's critique of *libertarianism* as an atomistic political outlook has been situated

[27] Atomism is discussed throughout a number of Taylor's published works. One particularly thorough examination is in his paper titled "Atomism" (Taylor, 1985e). Moreover, his critique of political atomism relates to his examination of negative liberty (Taylor, 1979). Negative liberty construes freedom in terms of individual independence from others, whereas positive theories relate freedom with collective political engagement.

intellectually within the *communitarian* line of political thought; which might otherwise be stated as *republican* or *civic humanist* by various authors.[28]

In light of the discussion of Taylor's malaises of modernity and the moral malaises of modern pediatric medicine highlighted earlier in this thesis, political atomism can be manifested in medicine in a number of ways. One apparent manifestation in medicine in general (i.e., not exclusive to pediatrics) is the political force that fosters privatized health care – a force that has been consistently influential in the United States and has been growing in Canada. A primary political backdrop to this is the libertarian view that individual persons should have a right to obtain services (e.g., health care) that they have the means to obtain. Within a libertarian view, systems that attempt to equalize the distribution of wealth so that all members of a community or society can have equitable access to these services could be regarded as impeding the rights of those who have the means to obtain better or more rapidly available services.[29] Within this outlook, individuals are not considered to have any obligation toward the collective (e.g., to help advantage the disadvantaged), other than participating in ways that can help ensure one's own personal benefits; such as contributing to a private health care insurance that would provide the benefits that the contributor desires - systematically excluding others who cannot afford such an insurance.

It is noteworthy that Canada and a number of European states have actively resisted highly privatized health care, favoring more socially equitable redistributive universally-accessible health care systems. This suggests that a libertarian atomistic political model of

[28] For a review of communitarian critiques of libertarianism, see Bell (2005).
[29] Norman Daniels – among others - has published a number of examinations of the political systems underlying the structure of health care and the distribution of related resources, as well as the equities/inequities that can result from various political orientations. For example, see Daniels (1985).

medicine is not a necessary consequence of modernity.[30] A number of forces affect societal orientations toward their respective political structure and substantive basis of health care provision (e.g., pulling toward libertarian or communitarian political outlooks). For example, a number of prominent medical organizations in North America have actively opposed the development of universalized (i.e., more communitarian) health care systems. For instance, physicians in Saskatchewan mounted a province-wide general strike in 1962 to contest the government's Medicare bill, as Saskatchewan was leading the way in the introduction of universal state-funded health care in Canada.[31] That is, medicine has at times actively promoted political atomism in health care.

Political atomism can also be manifested at the micro-political level of the clinical encounter. In contemporary bioethical discourse, the physician-patient relationship is commonly construed as "fiduciary"; as a relationship of trust.[32] That is, the patient should be able to trust that the physician's actions will be centered on the patient's interests. Indeed, the fiduciary relationship requires that the physician ensures that his/her actions toward one patient are not adapted to accommodate the needs of others – each patient should be treated according to his/her own individual interests. The patient's health care interests have become commonly defined in terms of the individual patient's treatment preferences, as expressed through informed consent or refusal of treatment. As discussed earlier in this chapter, contemporary medicine is highly anchored in one primary ethical principle: respect for patient autonomy.[33] "Good" medical practice is required to ensure that

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[30] Indeed, Taylor argues that none of the malaises of modernity are necessary outcomes of modernity. Societies can and do counter these malaises (Taylor, 1991).

[31] Source: The Encyclopedia of Saskatchewan, operated by the University of Regina (http://esask.uregina.ca/entry/doctors_strike.html).

[32] See Cassell (1985) for a thorough review of the physician-patient relationship.

[33] Although many bioethical frameworks attempt to relate autonomy to other ethical principles (e.g., Beauchamp and Childress' four-principles framework), respect for autonomy commonly stands out as an

treatment is adapted to the individual patient's preferences. This individualistic orientation has been adapted to the context of children, where treatment decisions should be adapted to the interests of an individual child-patient.[34] The impact that these treatment decisions could have on others (e.g., other family members, HCP, health care services available to other persons) may be considered psychologically important and meritorious of psychosocial support, yet this impact is not commonly attributed legal and ethical importance. It is generally held that a good medical plan should be centered on the individual patient. Moreover, the physician should keep confidential the patient's treatment choices,[35] even if the physician believes that other persons would be deeply interested in knowing about the patient's choices or that the patient's choice is contrary to the patient's health and wellbeing.

This fiduciary political framework for the physician-patient relationship has made important contributions toward countering moral concerns relating to paternalistic medicine (e.g., early pediatric medicine was oriented primarily to promoting child health in order to promote state economic and military interests). It can however perpetuate Taylor's concerns regarding political atomism if the clinical encounter is not grounded in a broader moral foundation. The individual choices and actions of a single patient and physician can be morally meaningful for others as well, both in terms of fairness in the distribution of limited health care resources, but also in terms of the regard of others toward the wellbeing of the patient and the inter-relationships of their respective wellbeing. For example,

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implicit higher order moral imperative. As described earlier, this seems attributable to the convergence of law and ethics and the primacy accorded to individualism in modernity. It is indeed noteworthy that Beauchamp and Childress (2001) included the principle of justice in their framework. Respect for autonomy should not necessarily entail a disregard for the goods of others – yet this ethical viewpoint is not borne out in corresponding legal norms.

[34] This is operationalized primarily through the *best interests* standard, but also with informed consent to some degree in older minors.

[35] Unless there is reason to believe that the patient is legally incompetent.

consider the case of an adult patient diagnosed with advanced cancer who chooses to forego treatment - without disclosing the diagnosis to his/her family and community of friends and other personal affiliations - because he/she does not want to be a "burden" to his/her family. The physician may try to counsel the patient on considering the merits of explicitly involving the patient's family and/or broader social network in making such a decision – both for the patient's benefit in that he/she may be misinterpreting the views of his/her family and social network on burden but also for the benefit of others (e.g., family and friends) who may wish to assist with the patient's care needs and may in fact be upset at the possibility of losing their loved one without attempting medical control of the problem. However, the physician has no legal obligation or duty toward these others. This is generally corroborated by commonplace bioethical models.

Indeed, the clinical encounter, as it is characterized in its ideal form, can bear all three features of Taylor's modernity: a relationship centered on the patient's (individualistic) autonomy, (atomistically) without concern for the wellbeing of others, practiced with (instrumentally reasoned) disengagement.

Taylor's account of disengagement in modernity draws on Descartes' separation of knowledge from action, striving to engage in reason in the search for certainty, without the distortion that can result from subjective perspectives (Taylor, 1989).[36] Disengagement has been fostered as an ideal for medical judgement as well.[37] Some commentators have

[36] The philosophical basis of disengagement in modernity is discussed in chapter 1.

[37] For a detailed discussion of concerns relating to medical disengagement, see: Betan (1997), Carson (1990; 2011), Cassell (1985), Daniel (1986), Svenaeus (1999; 2003), Thomasma (1994), and Zaner (1988), whose work is discussued larglely in the introductory chapter and in vaious other sections of this thesis. Disengagement has been adapted as an objectivist framework within normative standards for professional practice because it is generally regarded as necessary to (a) ensure objectivity in clinical judgment (i.e., to ensure instrumental reason in clinical practice) and (b) guard against the blurring of boundaries between professional and personal relationships, which can result in conflicts of interest and/or burnout. Characterizations of "burnout" commonly involve an excessive personal immersion in one's professional life.

discussed how the ideal of *rational disengagement* in medicine can foster dehumanization and forms of *relational disengagement* as well as *moral disengagement* in medicine.[38,39,40,41] It is argued that the objectified disengaged relationship that has become

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For a comprehensive review of *burnout* among HCP – including ethical considerations – see: Canoui and Mauranges (2004).

[38] Examinations of the clinician-patient relationship, as discussed by Cassell (1985), Schultz & Carnevale (1996), and Zaner (1988), draw together a number of substantively distinct yet potentially overlapping concepts. Disengagement is conventionally referred to in medicine as a rational-objectivist ideal that requires the containment of the subjective aspects of the relationship – as described further in a subsequent footnote below. This can be seen as laying a foundation for the emergence of "relational disengagement" (i.e., in order to suppress the "threat" of subjective affiliations upon disengaged rational functions) as well as "moral disengagement" (i.e., whereby moral commitments and responsibilities are construed narrowly within the confined immediate practical medical functions to be performed as discussed in a footnote below). These concepts intersect conceptually with "detachment" and "professional distance", whereby the relationship can become construed (and idealized) in exclusively instrumental terms. For example – drawing on a Taylorian modern backdrop of individualism, instrumental reason, and political atomism - heart surgery can be construed in terms of technical efficacy and expedience, whereby the goals of medicine become centered on ensuring that the physiological functioning of the heart is optimized (i.e., according to standardized objective measures of heart function), while balancing related resource costs. Rational, relational, and moral disengagement, as well as "detachment" and "professional distance" can converge in medicine as manifestations of (Taylor's modern) individualism, instrumental reason, and political atomism.

[39] *Moral disengagement* is a social psychological concept whereby a person detaches oneself from one or more ethical standards in a situation and excuses one's own actions or inaction in the face of a moral problem. For a review of moral disengagement, see: Bandura (1999) and Detert, Treviño, & Sweitzer (2008).

[40] For discussions of how moral disengagement can become manifested in medicine, see: Haque & Waytz (2012), Halpern (2001), and Dineen (2012).

[41] Rational, relational, and moral disengagement can relate – in part - to what is generally referred to as "professional distance". This is sometimes characterized as an impersonal "disinterested" medical stance (i.e., "disinterested" in this case is generally considered to imply avoidance of conflict of interest, yet insinuates how this can come to appear like personal disinterest, in an apathetic sense). This can in part be traced to professional norms regarding personal boundaries in clinical practice. For example, modern pediatric medicine requires a "professional distance" between clinicians and the children and families that they care for. This norm applies to all medical practice and is consistently formalized in medical codes of ethics and professional practice standards published by medical societies. Among the many rationales supporting this norm, *professional distance* has important ethical significance in that it alerts HCP to the power imbalances inherent in clinical relationships and the significant harms that can result from transgressions of some professional boundaries. Not only is a "personally distant" clinical relationship considered possible, it is commonly regarded as an ideal condition for clinical judgment. Although these reasons appear meritorious, *professional distance* has also been critiqued on substantive and ethical grounds, out of concern that it can become operationalized as relational and/or moral disengagement. That is, some scholars have argued that sound clinical judgment requires a significant personal engagement with a patient; i.e., professional and personal proximity. In medicine, this enables the physician to discern the particularities of the patient's clinical condition within a clinical relationship of proximity, trust, and respect wherein (a) the patient will feel able to fully disclose how his/her condition is manifested in day-to-day life and (b) the physician will be optimally attuned to the patient's specific clinical trajectory and patient's mode of representing his/her condition. For further discussion of this view, see: Cassell (1985), Schultz & Carnevale (1996), and Zaner (1988). In other words, an engaged clinical relationship can foster an empathic relationship between a physician and patient. The sense of empathy implied here refers to achieving a strong grasp of both the specific clinical details relating to a patient's condition as well as his/her emotional experience (i.e., empathy is commonly construed narrowly only in terms of the latter, discounting the former in its importance toward

idealized in modern medicine enable HCP to distance themselves from moral engagement with their patients and the broader community of potential patients, preventing these HCP from sensing moral commitments beyond the instrumental immediacies of the presenting medical problems. For example, the physician-patient relationship can become narrowly focused on the instrumental functions that the two parties "contractually" commit to (e.g., chemotherapy or surgery), without regard for any broader moral considerations, such as the implications for other family members or for community resources. The ideal of disengagement in medicine can foster another form of political atomism, whereby the physician – as well as other HCP - can distance him/herself morally and justify inattention to concerns beyond his/her atomistically defined local functions.

In turn, it is understandable that medicine would not necessarily foster political agency toward advocating for the resolution of politically-relevant medical concerns. For example – revisiting a dilemma that was discussed earlier - although it is widely accepted that parents can request to have life-sustaining treatments withdrawn from children with a projected grave prognosis, a clinician may note that over time there is a systematic "pre-judgment" among most parents against life with disability that appears to be a form of covert discrimination or even "eugenic engineering" that actively favors some persons over others. Yet, as long as the procedures surrounding the determination of each child's *best interests* are followed, the clinician is generally not required (and possibly not allowed) to act as a political advocate for the disabled. It is "necessary and sufficient" to follow the *best interests* procedures for each case. In fact, disability advocacy could risk being seen as a form of bias, as each case is supposed to be decided "objectively" in terms of the individual

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achieving a sound understanding of the patient's condition. For a hermeneutically-oriented discussion of empathy, see Schultz & Carnevale (1996).

child's *best interests*. Some accounts have described occurrences that on the surface might appear as counter-examples to the previous concern, yet further demonstrate political atomism in medicine through a form of apparent moral disengagement. For example, some branches of medicine, such as neonatology, have aggressively pursued saving the lives of significantly disabled children, yet have largely limited their commitment to these children through resuscitative measures only. Many families feel abandoned by the medical teams that saved their child's life in the first place, as they are discharged into communities with seriously under-developed supports for managing the children's complex needs at home. It would seem to follow that politically-engaged medicine should consider the ongoing medical needs of these children at home as "part and parcel" of the goals of medicine; striving to ensure adequate community resources are developed.[42] Medicine appears largely silent in advocating for these forms of community support.[43]

Additional manifestations of political atomism that may be particular to pediatric medicine should be examined in future investigations.

Concluding Remark

This analysis of the moral malaises of modern pediatric medicine highlights the important illuminations that can be achieved through Taylor's philosophical framework and hermeneutical retrieval. The "findings" of this analysis shed light on important phenomena that need to be reconsidered in everyday pediatric medical practice, education, and normative development. Toward this end, in the next and final substantive chapter of this

[42] For detailed examinations of medical disengagement from supporting longer-term services for disabled children and their families, see: Levine (2005) and *Médecine sous influence* (2004).
[43] Some notable exceptions have been documented, such as United States initiatives to develop "The Medical Home" (The Medical Home, 2002).

thesis, I outline an adaptation of Taylor's ideas in a framework for pediatric bioethical practice.[44] I refer to the framework as *hermeneutical retrieval and rapprochement*.

[44] Although the discussion in the following chapter is oriented primarily to the practice of pediatric bioethics, it can be readily adapted to the practice of pediatric HCP in general as well.

Chapter 6: Hermeneutical Retrieval and Rapprochement

Background

The principal aim of this thesis is to conduct a philosophical examination of moral concerns relating to contemporary pediatric medicine, using Taylor's hermeneutical framework and his investigations of modernity. Toward this end, three principal moral malaises in modern pediatric medicine have been identified and analyzed.

Whereas the preceding chapters that have focused on the past, examining socio-historical shifts in SI relating to children in medicine, I turn to the future in this chapter. I examine "where we should go from here". Drawing on my articulation of Taylor's ideas for a philosophical examination of moral concerns in early and contemporary pediatric medicine, I develop a hermeneutical framework for the "prospective" practice of pediatric medicine and bioethics.[1] That is, I propose how emerging moral concerns in individual clinical cases and in pediatric bioethics in general could be addressed in a more substantive manner, through *hermeneutical retrieval and rapprochement*.

This builds on existing hermeneutical approaches for the practice of bioethics by articulating a framework with interpretive and reconciliatory scope that extends beyond the presenting "local" context.[2] This framework considers broader socio-historical *horizons* and *imaginaries* grounded on Taylor's expansive work in epistemological, ontological, political, and moral philosophy.

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[1] Although the primary focus of this thesis in the preceding chapters has been on ethical and moral concerns in pediatric medicine (i.e., the practice of pediatric HCP) - which has important implications for the practice of pediatric bioethicists – this chapter concentrates primarily on the practice of pediatric bioethicists and how it can be enriched in light of the investigation undertaken in the preceding chapters. Although I am turning to bioethicists to help lead the way in promoting a "hermeneutical paradigm shift" in pediatrics, this discussion is also relevant for pediatric HCP and how they can re-orient their practices in consideration of the analyses presented in this thesis.

[2] These previously-published hermeneutical approaches to bioethical practice are reviewed in the Introduction of this thesis.

Although this chapter examines how *hermeneutical retrieval and rapprochement* can be used for addressing emerging and anticipated ethical concerns, this can also be considered as a framework for regular (i.e., non-morally-problematic) clinical practice. It is oriented toward fostering rich reciprocal communication and understanding, which would be helpful for patients (i.e., adults and children), family members, as well as HCP. For example, *hermeneutical retrieval and rapprochement* can help elucidate and bridge divergent "explanatory frameworks" (e.g., different understandings of the body, illness, and medical treatments) that can exist between patients and families on the one hand, and HCP on the other hand. This can be particularly important in the context of cross-cultural diversity.

Hermeneutical Retrieval

This chapter builds on philosophical work I conducted in 1997, through a master's thesis in bioethics at McGill University (Carnevale 1997; 2005). In this initial work, I attempted to develop a "thick" conception of pediatric bioethical practice based on a partial adaptation of Taylor's work. I argued for the merits of a hermeneutical interpretive approach to clinical pediatric bioethics to examine the contextual basis of emerging moral concerns in clinical consultations and identify local moral meanings underlying these concerns. In turn, these concerns could be reconciled through a *rapprochement* of divergent moral outlooks (Taylor, 1992a), drawing on Taylor's adaptation of Gadamer's "fusion of horizons".[3] Rapprochement is discussed further in the following section.

[3] Gadamer's "fusion of horizons" (Gadamer, 1960/1994), as a foundational hermeneutical construal of understanding, is reviewed in chapter 1.

Upon completion of the analyses conducted for this thesis, it became apparent that I needed to revisit this earlier attempt, in order to develop a stronger hermeneutical framework for the practice of pediatric bioethics. In my earlier formulation, I focused predominantly on the contextual analysis of the presenting clinical case, using hermeneutical interpretation. Although this is a meritorious approach, the broader analysis developed in this doctoral thesis has highlighted that a Taylor-based hermeneutical analysis should also be mindful of the *horizons of significance* and SI within which the presenting clinical pediatric case is embedded. This can be achieved through Taylor's *hermeneutical retrieval*.[4]

Hermeneutic interpretation in the practice of pediatric bioethics should be modeled according to Taylor's construal of the "hermeneutical circle". This involves an analysis of "part-whole" relations. A serial reading of "parts" is undertaken and continually related to a provisional understanding of the "whole", striving to understand the underlying sense – through *hermeneutical retrieval*.

The "parts" of a presenting case or problem in the practice of pediatric bioethics can be examined through a "local" hermeneutical analysis.[5] The particularities of the case should be examined to identify all of the morally meaningful elements, in a manner that resembles ethnographic contextual analysis as described by Hoffmaster (1992).[6] This

[4] A related conception of a hermeneutically-attuned practice of pediatrics has also be construed in terms of *phronesis*, which has been articulated according to Taylor's philosophy by Schultz and Flasher (2011). A *hermeneutical retrieval and rapprochement* framework, as developed in this thesis, provides a more comprehensive orientation by incorporating *horizons of significance* and SI in the process of inquiry and *rapprochement* as a guide for reconciliation.

[5] The expression "presenting case or problem" is used throughout this chapter to imply (a) an individual clinical case and/or (b) a clinical problem that is drawn from a series of cases, both of which are commonly encountered by practicing pediatric bioethicists.

[6] In "Can ethnography save the life of medical ethics?", Hoffmaster (1992) has argued that bioethics should turn to the social sciences to develop analytical frameworks for examining the complex contextual considerations surrounding presenting ethical concerns.

"parts" examination seeks to identify the "local goods" – goods that are considered particularly meaningful by individuals or groups of individuals in the case. For example, the parents of the child in question may both share a particular moral outlook, grounded in a constellation of beliefs, values, and practices, which can differ from the outlook shared by the HCP. Moreover, such outlooks can differ between the parents of a child, between the parents and the child, or between the various HCP involved with the case. For example, in the case of Kandice at the beginning of this thesis (Gazette, 1994), a local (i.e., "parts") hermeneutical analysis can identify that Kandice's mother wishes to continue with long-term mechanical ventilation based on a personal conviction that life is valuable, regardless of the significant limitations that would be confronted because of physical disabilities. This conviction may or may not be rooted in a recognized religious faith orientation. Regardless, she may believe that life is sacred and should always be preserved. For her, the "sanctity of life" is a "local good", which she would uphold as if it was a *hypergood*.[7] On the other hand, the treating physician may consider that the value of a life of a child is relative to the projected future for that child; specifically, the extent to which that child will be able to actualize the kinds of activities that are commonly valued for children. From this outlook, severe disability could significantly limit a child's projected future and therefore compromise the value of the child's life. For this physician, the "quality of life" is a "local good", which he might uphold as if it was a *hypergood*.

[7] Although an individual agent may recognize a particular good as if it was a *hypergood*, an individual agent cannot confer *hypergood* status to a good. A *hypergood* refers to a collectively agreed-upon good that has been accorded the highest possible value by the "collectivity" (e.g., a community or a society), as discussed in chapter 1.

It should be highlighted that this discussion of Kandice's case is speculative; a local hermeneutical analysis would require an engaged examination of the actual views held by the various persons involved with the case.

To conduct a local hermeneutical analysis of a presenting case or problem, the pediatric bioethicist would need an analytical "model" to identify relevant sources and orient the analysis of information obtained through these sources.

A provisional "model" for a local hermeneutical analysis is outlined below. This is adapted from the *Guiding Questions* analytical structure developed earlier in this thesis for the identification and analysis of texts. These questions should be considered as provisional "starting points" for *hermeneutical retrieval*, from which follow-up questions should be formulated according to emerging lines of inquiry.

Guiding questions for "local" hermeneutical analysis.

To conduct a hermeneutical analysis of a particular case or problem in pediatric ethics, two categories of guiding questions are required: (1) Source identification questions and (2) Analytical questions.

Source identification questions.

These questions seek to identify which sources should be consulted. Sources can include persons or documents. Persons can include directly or indirectly affected people with relevant insights or interests, such as: the patient, family members, involved or uninvolved HCP, chaplains, scholars, lawyers, as well as medical, psychological, social, or child welfare experts, among others. Documents can include personal documents prepared by persons involved in case (e.g., written statements by patients or parents, patient

drawings, medical record entries by HCP) as well as other relevant document sources (e.g., institutional policies, professional standards, codes of ethics, laws, among others). *Source Identification Questions* aim to explicitly articulate how the search for sources should be conducted, and which sources should be included or excluded.

> *Sample questions*:
> Which persons should be consulted to identify morally relevant perspectives on the presenting case or problem?
> Which texts should be consulted to identify morally relevant perspectives on the presenting case or problem?

Analytical questions.

These questions articulate how the identified sources should be examined to elucidate the morally relevant perspectives on the presenting case or problem.

> *Sample questions that can be directed to personal disclosures and texts:*
> What conceptions of right/wrong, good/bad, just/unjust underlie this assertion?
> What does this mean?
> What deeper meaning(s) underlies this assertion?
> What is the source of this deeper meaning?
> Which meaning(s) are concealed?
> Which conceptions of right/wrong, good/bad, just/unjust are concealed?
> Which background *social imaginary* and/or *horizon of significance* is this meaning rooted in?

As stated above, this local hermeneutical inquiry can help identify the "local goods" that are involved in a presenting case or problem. This examination can highlight "diverging goods" – different conceptions of the goods related to treatment decision-making and care for the presenting case or problem.

These diverging views can precipitate relational tensions, as some participants may not be able to genuinely understand or respect the perspectives of others. For example, Kandice's parents may be committed to a "sacred" regard toward the value of life rooted in a religious worldview that requires humans to do everything possible to sustain life through

the medical knowledge and technologies that they believe are provided by God; ultimately relying on divine intervention to determine their child's outcome. On the other hand, Kandice's physician may appeal to a "relative" regard toward the value of life rooted in a worldview that requires humans to treat illness through the medical knowledge and technologies developed through science; ultimately relying on scientific projections for a specific child's quality of life outcome to determine whether life-sustaining measures should be maintained. It is foreseeable that these diverging views can result in communication difficulties, misunderstandings, a reciprocal sense of disrespect and distrust toward one's outlooks because the other is not supporting him/her, among other relational tensions.[8]

Moreover, this approach to local hermeneutical inquiry can retrieve underlying *horizons of significance* and SI, relating the "parts" analysis of a presenting case or problem to the broader "whole". A specific case or problem does not stand on its own. It stands against background *horizons of significance*, which is rooted in the broader SI. These serve as "webs of significance" against which persons derive their respective understanding of the good.[9]

These *horizons of significance* and SI – which reflect the "whole" perspective – provide an orienting perspective for the pediatric bioethicist's analysis of the "parts" of the case or problem. The parts are meaningful in terms of how they relate to the whole; the parts cannot be grasped without a substantive understanding of the overarching whole. A

[8] This tension corresponds with the numerous problems related to a "politics of difference", critiqued by Taylor in his development of a "politics of recognition" for inter-cultural discourse (Taylor, 1992a).
[9] The term "webs of significance" is drawn from a well-known description of cultural context articulated by hermeneutical anthropologist Clifford Geertz: "The concept of culture I espouse ... is essentially a semiotic one. Believing, with Max Weber, that man is an animal suspended in webs of significance he himself has spun, I take culture to be those webs, and the analysis of it to be therefore not an experimental science in search of law but an interpretive one in search of meaning." (Geertz, 1973, p.5-6).

substantive understanding of the overarching whole, achieved through *hermeneutical retrieval*, can serve as a form of "interpretive attunement". That is, this can help orient the identification of meaningfully relevant "parts" and their interpretation in light of the "whole" through a hermeneutical circle; continually enriching the bioethicist's understanding of inter-related "parts" and "whole".

A proposal for an "interpretive starting point".

The bioethicist's examination of a presenting case or problem should be oriented with an explicitated substantive conception of the "interpretive field". A case or problem does not emerge in an interpretive vacuum; a bioethicist does not investigate a case or problem without pre-understandings. The investigation conducted in this thesis can serve as an "interpretive starting point" for a bioethicist, drawing on the dominant *social imaginary* and moral malaises of modern pediatric medicine retrieved in this thesis, as well as Taylor's broader elucidation of the malaises of modernity. These provide a strong grounding for "interpretive attunement".[10]

The "dominant *social imaginary*" of modern pediatric medicine articulated in this thesis is centered on the *best interests* standard and characterized by three principal moral malaises. The conflation of ethics and law results in a substantively vacuous moral proceduralism, where pediatric bioethics is predominantly defined and practiced according the procedures of law. These procedures espouse reliance on a substantive standard: *best interests*. However, *best interests* is not anchored in any agreed-upon substantive moral content. This results in a circular proceduralism where *best interests* is defined by the agent

[10] The term "interpretive attunement" has been created for this discussion to imply a phenomenon that corresponds with Gadamer's (1960/1994) "fusion of horizons".

designated by legal procedure. The dominant conception of children as dependent and incapable (i.e., moral objects for whom meaningful matters are determined by parental and/or state agents), discounts an authentic recognition of children as moral subjects; their moral outlooks are systematically muted.

The dominant *social imaginary* and corresponding moral malaises of modern pediatric medicine are rooted in the broader malaises of modernity; i.e., individualism, instrumental reason, and political atomism. Attunement to this constellation of malaises (i.e., malaises of modern pediatric medicine and the malaises of modernity), can orient a pediatric bioethicist's identification of explicit and/or implicit distresses that can arise from these malaises.[11] Moreover, such an attunement can orient the *hermeneutical retrieval* of concealed goods and related *horizons of significance* that have resulted in various forms of moral malaise.

The convergence of law and ethics can conceal the full scope of morally meaningful aspects of both (a) a presenting case or problem and (b) the broader *horizon of significance* and SI. Attunement to this malaise can orient a bioethicist toward the retrieval of implicit, embedded, or concealed moral goods and related concerns, ensuring a richer grasp of the moral terrain in question. Attunement to the socio-historical construal of children as dependent and incapable can sensitize a bioethicist to the discounting of children as moral subjects and the muting children's voices. The bioethicist would seek to "unconceal" these dimensions of children's moral lives. Attunement to the ambiguous nature of *best interests* as well as "benefits and burdens", and the impracticability of a calculative weighing of the

[11] The term "orient" is used to imply a process of sensitization to the potential perspectives of those involved with a presenting case or problem in pediatrics, based on the malaises reviewed in this thesis. This does not imply a universalization or imposition of these malaises as absolute moral truths that necessarily apply in all contexts.

latter, can help a bioethicist recognize that "*best interests* assertions" are rooted in a diversity of commonly unarticulated *horizons of significance*, which obscures the underlying goods involved with the presenting case or problem. This would inform the bioethicist's attempts to retrieve these unarticulated horizons and discern how underlying goods can be related to a morally-substantive understanding of a particular child's *best interests*.

Turning to Taylor's own malaises of modernity, attunement to his concerns about individualism can unconceal the relational embeddedness of the "individuals" involved with a presenting case or problem.[12] Situations presenting as ethically troublesome, commonly resemble conflicts between persons in different vantage-points (e.g., parents vs. physicians, physicians vs. nurses, one parent vs. the other parent, child vs. parent(s), one medical specialist vs. another medical specialist). These persons are engaged in an intertwined network of commonly interdependent relationships, involving reciprocal communication, understanding, trust, respect, and power.[13] One person's assertion of his/her own conception of the good, generally impacts upon others and their corresponding conceptions of the good. The assisted-suicide that was sought by Marcel Tremblay (i.e., described in the previous chapter; Sorensen, 2005) was defended in terms of respecting the patient's autonomy. However, the assisted-suicide of Marcel Tremblay would require the cooperation of HCP, the police and the courts, as well as his family members and friends –

[12] Relational conceptions of human agency challenge pre-existing and dominant orientations centered on autonomy. Carol Gilligan's *In a Different Voice* (1982) which examined the moral psychological development of girls and women, highlighted that relational interdependence - rather than the exclusive pursuit of autonomy - was a central striving that characterized their development. Bergum and Dossetor (2005) as well as Stoljar (2011), among others, have articulated relational ethical frameworks for medicine.
[13] Levetown (2008) has published a comprehensive review of the clinical pediatric literature that highlights the complex interrelations and communication involved in the care of children and their families. Meyer and her colleagues (2009) have reported empirical findings that demonstrate how communication in the care of critically ill children involves complex relational abilities.

calling upon all of these agents' own conceptions of the good. Marcel Tremblay is much less of an individual than implied by his autonomy-based request for assisted-suicide. A hermeneutical pediatric bioethicist attuned to this malaise would seek to identify potential tensions between the modern striving for individualism and individuals' incontrovertible relational embeddedness.

Taylor has argued that the rise of instrumental reason in modernity has supplanted ontologically-grounded moral outlooks. In pediatric bioethics, this has resulted in a vacuous ontological moral ground; attempts to construe a child's *best interests* ultimately resort to a "morally ground-less" proceduralism whereby this standard is defined by whoever is designated to define it by legal procedures. This obfuscates the many moral goods involved in the various agents' strivings to ensure the child's good. An attuned pediatric bioethicist will systematically explore the various goods "at play" among all involved, seeking to retrieve the relevant substantive moral considerations.

Political atomism is Taylor's third malaise of modernity. As described in the previous chapter, this is manifested in modern pediatric medicine in various ways. Political atomism can become operationalized in forms of "relational disengagement" as well as "moral disengagement"[14] between clinicians and the children, families, communities, and societies that they care for, which can result from the dominant prototype of disengaged objectivity characterized for HCP. [15] That is, this can lead to multi-dimensional disengagement, characterized as HCP detachment from the lives of others (i.e., an idealized distancing from matters affecting others). These processes can result in a "personal"

[14] This can result in part through extensions of the idealization of "rational disengagement" as well as other manifestations of Taylor's malaises of modernity, as discussed in the previous chapter.
[15] I acknowledge that some HCP have actively attempted to counter this "ideal of disengagement", particularly within nursing. For examples, see Benner (1990; 1994a; 1994b; 1994c) as well as Benner and Wrubel (1988).

disengagement that can deprive patients from a humanized attentive model of clinical practice as well as deprive HCP from rewards that can result from an authentic personal investment in clinical relationships.[16] Moreover, this systematic detachment can become manifested as the widespread political atomism described by Taylor, whereby HCP decline any recognition of their political power and responsibility to act as political agents who can advocate for the interests of muted or marginalized populations, such as children; further contributing to the suppression of potential rewards that HCP can draw from their work.

According to Taylor, political atomism can result in personal as well as community and societal moral deprivations. An attuned pediatric bioethicist would uncover the concealed political dimensions of a presenting case or problem and foster political agency among the involved participants as well as the bioethicist's own political agency.

Throughout this process of *hermeneutical retrieval*, with interpretive attunement to the malaises of modernity and modern pediatric medicine, the pediatric bioethicist will "bring to light" the many goods and corresponding *horizons of significance* involved with a presenting case or problem. This will help identify potentially divergent *horizons of significance* that may underlie the presenting case or problem, which may have been concealed by dominant *horizons of significance*. These horizons can converge and diverge across many aspects of moral life, resulting in various forms of agreement and disagreement about what should be done.

These divergences can exist: (a) between persons (e.g., between parents believing in divine intervention that will bring their child a miraculous cure and physicians relying on

[16] In contrast, Cassell (1985), Schultz & Carnevale (1996), and Zaner (1988), among others, have published detailed discussions of the clinical (i.e., which ensure accurate patient assessments and sound treatment plans) and ethical (i.e., that foster respectful and trusting relationships) merits of relational engagement in clinical practice.

predictive scientific knowledge to "know" a child's death is immanent and inescapable); (b) between persons and the dominant horizon of significance (e.g., between a parent who believes that no moral distinction can be made between a fetus and a newborn because if it is permissible to end the life of a fetus with Trisomy 21 until late in pregnancy then this should also be permissible for a newborn infant with the same condition, which conflicts with accepted North American legal norms that recognize the newborn with Trisomy 21 as a person with a right to life)[17]; and (c) *within* individual persons because of the absence of a widely-accepted *hypergood* (e.g., a parent who believes that his/her child with severe disability is precious and entitled to live as full a life as possible while also believing that if it was him/herself with the disability, he/she would want to have life-sustaining treatments withdrawn and allowed to die; i.e., believing in both sanctity of life and quality of life with similar degrees of importance).

Hermeneutical Rapprochement

Taylor's examination of multiculturalism and a "politics of recognition" provides a hermeneutical framework for attempting the reconciliation of divergent *horizons of significance*.[18] Taylor relates multicultural tensions to the human need for recognition. He proposes a politics of recognition based on the premise

> that cultures that have provided the horizon of meaning for large numbers of human beings . . . over a long period of time - are almost certain to have something that deserves our admiration and respect . . . What it requires above all is an admission

[17] For a detailed discussion of the controversies underlying this problem, see Giubilini and Minerva (2012) for their examination of "after-birth abortion".

[18] Although some descriptions of other hermeneutical frameworks for bioethical practice have been published (for example, Carson, 1990), which outline hermeneutically-oriented strategies for addressing ethical dilemmas in clinical practice, I have turned to yet another domain of Taylor's philosophical contributions to develop an orientation for reconciling ethical dilemmas in pediatrics that is congruent with the body of Taylor's philosophy already articulated in this thesis as well as this framework for bioethical practice.

> that we are very far away from that ultimate horizon from which the relative worth of different cultures might be evident (Taylor, 1992a, pp. 72-73).

Adapting Gadamer's "fusion of horizons" (Gadamer, 1960/1994), this requires a transformation of existing standards and the development of a new vocabulary of what constitutes worth that those involved could not possibly have had at the beginning. This process does not try to identify which outlook is "right" or "most right". A politics of recognition seeks to arrive at a reciprocal understanding - a *rapprochement* - upon which to foster "cross-horizonal" understanding.[19]

The adaptation of *hermeneutical rapprochement* in pediatric bioethics orientates the practice of a bioethicist away from a role as a moral expert or arbiter, towards that of a mediational agent. As a mediating "agent of rapprochement", seeking to bridge divergent moral outlooks (i.e., *horizons of significance*), the bioethicist engages persons involved with the presenting case or problem in conversations that foster this process with a recognition of prevailing social and professional values, beliefs, obligations, norms, as well as relevant laws. These values, beliefs, obligations, norms, and laws may sometimes conflict with the moral outlooks of those involved with presenting case or problem, which sometimes precipitates or amplifies the emerging ethical concerns.

As divergent moral outlooks are identified through *hermeneutical retrieval*, *hermeneutical rapprochement* in the practice of pediatric bioethics should seek to identify "horizonal zones of moral convergence"; i.e., identifying common ground and common language among the outlooks that are involved. For example, agents could agree that

[19] The term "rapprochement" is a consistent extension of the title that was assigned to an earlier collection of Taylor's papers on Canadian federalism and nationalism; i.e, *Rapprocher les Solitudes* (Taylor, 1992b). The English version of this collection was entitled *Reconciling the Solitudes* (Taylor, 1993). It is noteworthy that in selecting a term for his subsequent essay on multiculturalism, Taylor opted for "rapprochement" rather than "reconciliation"; i.e., the French term rather than English. Taylor seemed to favor the tone of bridging implied by "rapprochement", congruent with Gadamer's "fusion of horizons" that inspired this notion.

despite their divergent views, they all (1) want what is best for the child, (2) wish to comfort the child's suffering, and (3) find acceptable means to achieve their respective conceptions of "best for the child" and "comfort suffering". *Hermeneutical rapprochement* recognizes that there is no pre-existing consensus on the ultimate goods that should be pursued; seeking a *rapprochement* of the various moral outlooks regarding the child: parents, physicians, nurses, other professionals, the institution, the state, recognized norms and standards, and the child him/herself.

In Kandice's case, the parents and the physicians are caught in a significant disagreement; whether or not her life should continue to be sustained with resuscitative technologies. This can understandably give rise to profound relational tensions, as the basis of the disagreement can involve foundational values and commitments toward doing what is right for children among parents and pediatric HCP. *Hermeneutical retrieval* can help identify the underlying substantive moral grounds for everyone involved with the case; speculations on what these might be were discussed above. In turn, *hermeneutical rapprochement* can foster shifts in the understandings of the others' outlooks, among parents, HCP, and others involved with the case; e.g., by highlighting the "morally good" basis for each participant's views. This can facilitate the identification of treatment goals that everyone can agree on, such as maximal control of Kandice's pain, distress, and suffering.

These "zones of convergence" can be further developed through ongoing *rapprochement*, which can also help resolve relational tensions resulting from divergent outlooks. It should be anticipated, however, that some aspects of the multiple *horizons of significance* may be incommensurable. For example, if the parents' outlook is rooted in religious faith (i.e., that a miracle can cure Kandice through divine intervention) and the

HCP views are based on a scientific model (i.e., that Kandice's grave prognosis can be conclusively confirmed through predictive science), it should be recognized that *hermeneutical rapprochement* may not bridge substantively divergent explanatory grounds. Although *rapprochement* may not reconcile some horizonal differences, it can nevertheless foster continually clearer reciprocal understandings among those involved in the case. The parents may not agree with the physicians' proposal to withdraw life-sustaining treatments, but can come to understand that the basis of the physicians' views is rooted in deep regard for the child's quality of life and suffering. Whereas the parents' may have initially inferred that the physicians wanted to withdraw mechanical ventilation because they devalued the importance of Kandice's life or did not think she was worthy of such an investment in limited resources, the parents may come to understand that the physicians' reticence is in fact based on their commitment to do what they understand is good for Kandice, that they cannot bear to prescribe medical treatments that they believe are predominantly harmful. Likewise, whereas the physicians may have initially believed that the parents' refusal to withdraw mechanical ventilation was based on a psychological denial of the confirmed scientific facts regarding Kandice's prognosis or parental belief in "fanatical" religious doctrine without consideration of the child's current and projected suffering, *hermeneutical rapprochement* can help physicians understand that the parents clearly understand the scientific facts, but they interpret such facts within a faith-based moral order that attributes great value to Kandice's life despite the limitations that she may live with. Although the parents wish for a miraculous cure, they may also understand that this is highly unlikely but are nevertheless committed to assisting Kandice toward whatever life "God defines for her". As stated above, these considerations regarding Kandice's case are entirely

speculative. In bioethical practice, these areas of horizonal convergence and divergence should be elucidated through *hermeneutic retrieval*.

In addition to being attuned the malaises of modernity and modern pediatric medicine as well as malaises arising from divergent *horizons of significance*, the pediatric bioethicist should also be attuned to malaises that can emerge through the process of *hermeneutical rapprochement*. For example, parents who are Jehovah's Witnesses may come to fully understand that withholding blood products from their child will actually result in their child's death, as the physicians predicted. The parents can find themselves confronted with irreconcilable beliefs and values: upholding their religious commitment to refrain from engaging in a horrible spiritual act[20] versus ensuring the survival of their beloved critically ill child. Likewise, physicians can come to a shifted understanding and regard for parents who are Jehovah's Witnesses, recognizing the profound spiritual torment that blood transfusions imply within this community. Physicians can find themselves in a moral bind between practicing according to accepted standards of scientific pediatric practice (i.e., providing blood transfusions to children in hemorrhagic shock) and demonstrating regard for parental wishes and family cultural and religious continuity. Thus, *hermeneutical retrieval and rapprochement* involves an ongoing process, continually examining and engaging the unfolding moral terrain.

[20] That is, the "consumption" of human blood is strictly prohibited among Jehovah's Witnesses, even if it is needed to save life. This position is examined in renowned court judgments involving Jehovah's Witnesses, such as: *A.C. v. Manitoba*, 2009 ; *B.(R.) v. Children's Aid Society of Metropolitan Toronto*, 1995; *Malette c. Shulman*, 1990.

Normative Development in Pediatric Bioethics

The discussion in this chapter has focused primarily on the practice of pediatric bioethics in the context of clinical cases or problems. A pediatric bioethicist can also practice *hermeneutical retrieval and rapprochement* for normative analyses and development.

Bioethicists are frequently called upon to examine existing ethical norms or develop new articulations of norms for emerging ethical concerns in pediatrics (e.g., development of ethics policies, guidelines, standards, position statements, or legislative changes). Analyses of emerging ethical concerns in pediatrics regarding the cessation of medically-administered nutrition and hydration, life-sustaining interventions in the context of severe disability, or "medically-assisted death"[21] – for example – can be commonly narrowed to polemic legalistic considerations; respectively considering: medically-administered nutrition and hydration in children as a necessity of life or a medical treatment; sanctity of life - even a severely disabled life - versus a consideration of the worth of a life as relative to the "quality of life" that can be undertaken; the rights of parents to mandate a medically-assisted death for their child in the context of terminal illness versus a universal prohibition toward the active ending of life as a permissible goal of medicine. *Hermeneutical retrieval* would seek to trace the substantive moral foundations underlying these polemic considerations, elucidating how these are morally meaningful, while identifying additional moral concerns involved with such problems. This process will sometimes find that some views may in fact be less polemic than they appear (e.g., sanctity of life and quality of life

[21] "Medically-assisted death" is a translation of a term recently proposed by a Quebec Paliamentary Commission; i.e., "l'aide médicale à la mort". This Commission was mandated to examine "dying with dignity". For a media report, see (http://www.lapresse.ca/actualites/quebec-canada/politique-quebecoise/201203/22/01-4508229-une-commission-parlementaire-dit-oui-a-laide-medicale-a-la-mort.php).

can become recognized both as foundational and incomparable goods, where one cannot be subordinated to the other in a modern SI where there does not exist one agreed-upon *hypergood*).

In turn, normative development would then seek to undertake a *hermeneutical rapprochement* of these apparently divergent moral goods, articulating practice orientations that are as attuned as possible to the ensemble of moral considerations for a given problem. For example, normative development through *hermeneutical retrieval and rapprochement* would recognize and seek to reconcile the *best interests* of children with the interests of families, HCP, as well as institutional and societal resources – elucidating the full scope of morally important goods that are in question. As with case-based bioethics practice, *hermeneutical retrieval and rapprochement* in normative development involves an examination and engagement of the full scope of the unfolding moral terrain.

Conclusion

The principal aim of this thesis was to examine moral concerns relating to contemporary pediatric medicine, drawing on Taylor's hermeneutical framework and his investigations of modernity. This required an articulation of Taylor's hermeneutics as a philosophical "methodology" that could be used for this analysis, as well as an explicitation of his examination of modernity to outline provisional *horizons of significance* and SI against which modern pediatric medicine could be better understood.

The emergence of pediatric medicine in the modern era was traced, highlighting the corresponding shifts in moral orientations toward children in medicine; from a primarily utilitarian outlook to a more humanitarian child-centered orientation grounded on the *best-interests* standard. This analysis identified three principal moral malaises in modern pediatric medicine: (a) the convergence of law and ethics; (b) the construal of children as incapable and dependent; and (c) the ambiguous nature of *best interests*. These malaises were further examined to retrieve the background *horizons of significance* and SI against which they have taken shape.

A Taylorian framework for the practice of pediatric bioethics was also articulated; i.e., *hermeneutical retrieval and rapprochement*. This can enhance the richness of bioethical practice through interpretive attunement and reconciliation of commonly concealed moral considerations.

This thesis makes a contribution to a slowly developing domain of philosophical inquiry that can be referred to as *philosophy of childhood*,[1] through the moral malaises that were identified as well as the articulation of a philosophical framework for examining the moral dimension of childhood. The latter also advanced another growing field of inquiry, the *philosophy of Charles Taylor*,[2] by articulating a Taylorian framework for examining moral philosophical concerns in medicine as well as a framework for pediatric bioethical practice.

Future work could adapt these two frameworks (i.e., one for philosophical investigations and the other for bioethical practice) and formulate a Taylorian methodology for empirical qualitative research. Some important development in this domain has already been achieved, giving rise to a number of valuable empirical insights, particularly in the health sciences. One especially prominent researcher, nursing researcher Patricia Benner, has drawn heavily on Taylor's hermeneutical philosophy.[3] This can be enriched through

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[1] The philosophy of childhood, a developing field of philosophical inquiry, draws on theoretical work in psychology, education, law, and political theory (among others), as well as moral philosophy. Some of the themes examined in this domain include agency and childhood (i.e., moral agency, legal agency, political agency) (Archard, 2004; Archard & Macleod, 2002; Coles, 1986; Houlgate, 1980; Matthews, 1980; 1994; Turner & Matthews, 1998; Wringe, 1981), cognitive and moral development (Cohen, 2002; Gilligan, 1982; Kagan & Lamb, 1987; Kohlberg, 1981; 1981/1984; Piaget, 1929; 1932/1965), and research ethics (McCormick, 1974; Ramsey, 1970; 1977).

[2] A growing body of investigations is examining Taylor's work as a focus of philosophical inquiry in itself; giving rise to a "philosophy of Charles Taylor". These works conduct critiques, interpretations, extensions, and integrations of Taylor's ideas. As discussed earlier, some of this work has examined his philosophy broadly (e.g., Abbey, 2004a; Gagnon, 2002; Smith, 2002; Tully, 1994), or has focused on specific domains such as modernity (e.g., Laforest & de Lara, 1998) or political philosophy (e.g., Redhead, 2002; Pélabay, 2001). Additional inquiries have examined how Taylor's philosophy can inform the development of ideas and frameworks in domains he himself did not examine, such as philosophy of medicine (Carnevale & Weinstock, 2011) and empirical qualitative research methodology (Benner, 1994a). The latter is described below. Additional works in the "philosophy of Charles Taylor" are discussed throughout this thesis – including, of course, Taylor's own publications.

[3] Patricia Benner, a nursing researcher, is a highly acclaimed empirical qualitative researcher in the health sciences. She drew on Taylor's hermeneutical philosophy, along with Hubert Dreyfus' epistemology (Dreyfus & Dreyfus, 1996; Dreyfus, Dreyfus, & Benner, 1996) and Heidegger's existential phenomenology, to develop a highly recognized methodology that she refers to as "interpretive phenomenology" (Benner, 1994a). Benner has used this methodology to examine clinical expertise and education in nursing (Benner, 1984; 1990; 1994b; 1994c; Benner, Hooper-Kyriakides, & Stannard, 1999; Benner, Sutphen, Leonard, et al., 2009), among others.

further articulation in light of Taylor's recent work on SI. SI enable hermeneutical qualitative research to examine the broader social context surrounding a research concern (i.e., in addition to the presenting immediate context), which would bring a valuable innovation to hermeneutical empirical qualitative research.[4]

Several phenomena highlighted in this thesis should be further examined in future philosophical inquiry. Some priorities for further investigation include: the moral relevance of the voice of the child and the consideration of children as moral agents; the complex inter-related responsibilities for children among parents, HCP, and state bodies; and a re-articulation of the *best interests* standard with a better-developed substantive moral groundwork. Moreover, the three malaises identified in this investigation require further research and additional malaises in pediatric medicine should be identified and examined.

Normative research and development is needed to examine ethical standards relating to the concerns highlighted in this thesis. For example, the priorities listed in the previous paragraph should be addressed. To illustrate, the multiple perspectives highlighted that relate to children's insights and decisional capacities regarding their own health requires a re-thinking of the operationalization of consent and assent standards in pediatric medicine. Further research is required to examine the specific ways in which these standards should be "updated" to bring them in line with current understandings of childhood.

A major domain of the "ethical lives of children in medicine" was not examined in depth in this thesis; i.e., pediatric research ethics. Developments in this domain were

[4] I have already initiated this work toward developing a Taylorian framework for empirical qualitative research with two initial publications: (a) *Charles Taylor, Hermeneutics and Social Imaginaries: A framework for ethics research* (Carnevale, in press) and (b) *Moral experience: a framework for bioethics research* (Hunt & Carnevale, 2011).

outlined in the analysis of the emergence of *best interests*, but the thesis has concentrated primarily on clinical ethical considerations, as this was the principal focus of the thesis. Future philosophical and normative research should consider the merits of conducting a Taylorian investigation of ethical concerns relating to children participating in research, drawing on the findings of this thesis (e.g., problems relating to the congruence of ethics and law, the construal of children as incapable and dependent, or the ambiguous nature of *best interests*).

The elucidation in this thesis of important moral considerations that are commonly concealed in pediatric medicine highlights the importance of promoting a shift in the usual representations of ethical concerns in this field of medicine. *Hermeneutical retrieval and rapprochement* presents a framework for such a shift in the practice of pediatric bioethics; a shift toward a more substantive conception of the moral terrain underlying childhood and pediatric medicine, as well as an approach to potentially conflicting moral outlooks that seeks reconciliation (rather than arbitration) between outlooks; striving to be attentive to the full scope of morally meaningful considerations.

This framework could be adapted for the everyday practice of pediatric HCP (i.e., not only bioethicists), so they can be optimally attuned to background moral *horizons* and *imaginaries* as well as strategies for bridging (i.e., "fusing") divergent outlooks. This could foster the development of a more morally substantive conception of practice among pediatric physicians, nurses, and other HCP; turning to pediatric bioethicists when needed for the examination and reconciliation of more complex situations. The development of a hermeneutical framework for "everyday pediatric practice" could also provide a rich model for clinical pediatric education, orienting clinicians to the moral complexities of childhood.

An adaptation to pediatric practice of the insights brought to light by this investigation can foster a more morally-attuned orientation to situations like the case of Kandice (Gazette, 1994). The tension between Kandice's mother and physician was presented as a conflict over what course of action would serve her *best interests* – withdrawing or continuing mechanical ventilation. Attunement to the complex socio-historical background leading to contemporary understandings of childhood and the concealed moral malaises in modern pediatric medicine - with a Taylorian hermeneutical framework - can bring to light how the reconciliation of a case such as this requires more than a "proceduralist" determination of who should judge Kandice's *best interests*. Rather, an important end in itself is a process of thorough examination and unconcealing of background moral considerations and the pursuit of ongoing agency that attends to a broad consideration of all that is morally meaningful for Kandice and those affected by the situation.

Ethical pediatrics should be defined not only by decisional outcomes, but by the depth of the ethical analyses undertaken to arrive at those outcomes. In turn, this can also help ensure the richest possible ethical outcomes.

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