Why the Little Mermaid stopped singing:

How oppressive social forces silence children's voices, and rob them of the opportunity to develop and exercise autonomy in the health care context

Lori Seller
Philosophy Department,
McGill University, Montreal
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Abstract:

The “new sociology of childhood” replaces the historical notion of children as inherently vulnerable, helpless and in need of protection, with a perception of children as capable of competent, autonomous, social participation. Although this new sociological perception underlies current children’s rights literature, Canadian common law, and important Canadian pediatric health care guidelines, children’s autonomy in health care contexts remains easily denied or subverted in favour of adult conceptions of their best interests. In order to try to understand why, I use a feminist, *relational* approach to autonomy to analyze how oppressive social forces might hinder children from developing and exercising their autonomy in health care, and uncover a tendency to silence the voice of the child within bioethical discourse. These results suggest that greater levels of pediatric autonomy could be fostered by overcoming oppressive social forces and by fostering the skills necessary for the development and exercise of autonomy.

Résumé:

L’ancienne notion prévalant des enfants vulnérables, délaissés et nécessitant de la protection est aujourd’hui remplacée par une perception d’enfants capables de compétence, d`autonomie, et de participation sociale. Il s’agit de la « nouvelle sociologie de l'enfance. » Bien que cette nouvelle perception sociologique soit à la base des droits courants des enfants, du droit coutumier canadien et de directives canadiennes importantes sur la santé pédiatrique, l'autonomie des enfants dans le contexte de la santé demeure facilement niée ou renversée par des perceptions d’adultes qui prétendent agir pour les meilleurs intérêts des enfants. Afin d'essayer d’en comprendre le pourquoi, j'utilise une approche féministe « relationnelle » à l'autonomie qui me permet d’analyser comment les forces sociales oppressives peuvent gêner le développement et l'exercice de l’autonomie pédiatrique dans le domaine de la santé, pour alors découvrir une tendance à amortir la voix de l'enfant dans le discours bioéthique. Ces résultats suggèrent que de plus hauts niveaux d'autonomie pédiatrique pourraient être stimulés en surmontant ces forces sociales oppressives et en donnant la priorité au développement des compétences nécessaires pour l’exercice de cette autonomie.

Introduction:

In the original Hans Christian Anderson fairy tale *The Little Mermaid*, upon which the Disney version of recent past is loosely based, the Little Mermaid saves a prince from drowning when his ship is wrecked in a storm. She falls madly in love with the prince and becomes infatuated with the idea that when humans die, they enjoy eternal life whereas mermaids merely evaporate, becoming foam on the sea. Having been told by her grandmother that if a mortal truly loves a mermaid and marries her, a piece of his soul will become part of her and they will both enjoy eternal life, the Little Mermaid conspires to make the prince fall in love with, and marry her.

Knowing that the prince will never accept her with her mermaid's tail, she visits the sea witch who agrees to give her a potion that will change her mermaid tail into legs, but only if she will give up her beautiful singing voice. Needing human social acceptance if she is to have a chance at winning the love of the prince, the Little Mermaid agrees to allow the sea witch to cut out her tongue, thereby giving up her voice, and goes to live in the prince's kingdom with her new pair of legs. Sadly though, the prince, although fond of the little mermaid, falls in love with a princess from a neighbouring kingdom whom he mistakenly believes saved him from drowning, and marries her instead. Just before succumbing to a broken heart, the Little Mermaid hurls herself back into the sea, and mercifully, is transformed into an immortal air fairy.

The symbolism of the Little Mermaid's willingness to silence her own voice in an attempt to win human social acceptance and the love of the prince is a fitting metaphor for my thesis. In the context of pediatric autonomy in health care, I will show that despite strong theoretical acceptance of pediatric autonomy, it remains easily subverted by adult interests in practice. Using a feminist "relational" approach to autonomy to uncover oppressive social forces at play, I demonstrate how the voices of children are silenced by oppressive social cues that send strong messages to children that undermine: the nature of their role in the patient-parent-physician triad, the importance of their perspectives, and the value of their participation in health care decision-making on their own behalf. In an attempt to comply with the clear social norms and expectations with which they are confronted, children remain silent and are robbed of significant opportunities to develop necessary skills, or exercise their autonomy, even in the presence of sufficient cognitive skills.

In classic Western bioethical ideology, respect for a patient's autonomy is of utmost importance and is respected whenever possible. The word autonomy is derived from Greek and literally translates into "self-rule." However, autonomy involves more than the mere ability to make choices, and respect for a patient's choice is not absolute in bioethics. To be autonomous is to make choices and act according to a rational plan developed with respect to one's personal goals and values; therefore, to be considered autonomous and to merit respect for one's choices, patients must demonstrate certain capacities. They must be able to understand information relevant to the choice, act intentionally, and do so in the absence of coercive or controlling influences.[1]

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[1] Beauchamp, T. and J. F. Childress (2009). Respect for Autonomy. Principles of Biomedical Ethics, Sixth Edition. New York, Oxford University Press**:** 99-148.

Children however, were historically assumed to be incapable of understanding pertinent issues, weighing risks and benefits, making rational decisions, and coping with knowledge about their own illness; therefore, they were not considered capable of autonomy, and were usually excluded from the medical decision-making process altogether. Adding to the problem was the fact that the general concepts most often referred to that grant adults the firm right to make their own health care decisions, such as legal competency and mental capacity, are more difficult to apply to the pediatric population. Age-based theories of development reinforced this exclusionary rationale and justified the complete denial of children’s autonomy.

Feminist bioethics has criticized the traditional concept of autonomy and its use in bioethics in several ways that also happen to highlight its insufficiency for application to pediatric populations. They have argued that the traditional view of autonomy is an individualistic ideal that few patients can meet. Instead, feminists assert that autonomy is best thought of as a set of skills that equip a person to make decisions in keeping with their personal values and priorities.[2] On the feminist understanding, autonomy admits of degrees, and a person might be capable of autonomous decisions in one or several local areas, while globally, their autonomy remains not yet fully developed.

Thanks in part to this kind of criticism, it has now been realized that children are much more capable of medical decision-making and coping with illness than was previously thought. This realization has translated into a

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[2] Meyers, D. (1989). Autonomy Competency. Self, Society, and Personal Choice New York, Columbia University Press.

concentrated investigation of pediatric capacities for autonomous decision-making and yielded a more inclusive approach to involving children in their own health care.[3, 4, 5]

Over the years, significant progress in terms of the theoretical recognition of pediatric autonomy has been made. The 2004 position statement issued by the Canadian Paediatric Society entitled, "Treatment decisions regarding infants, children and adolescents," reflects a commitment to pediatric involvement in health care decision-making and respect for their autonomous choices. For example, the position statement asserts that, "children who have partial skills to make decisions should be recognized as having some authority over their own health care,"[6] and, "once they have sufficient decision-making capacity, they should become the principal decision-maker for themselves."[7] Furthermore, Canadian Supreme Court Justice J. Abella explains that,

> The latitude accorded to adults at common law to decide their own medical treatment had historically narrowed dramatically when applied to children. However the common law has more recently abandoned the assumption that all minors lack decisional capacity and replaced it with a general recognition that children are entitled to a degree of decision-making autonomy that is reflective of their evolving intelligence and understanding.[8]

However, despite the development of a large body of legal, ethical and philosophical literature on the topic of pediatric autonomy, fundamental gaps

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[3] Bluebond-Langner, M. (1978). The Private Worlds of Dying Children. Princeton, Princeton University Press.

[4] Alderson, P., K. Sutcliffe, *et al*. (2006). "Children's Competence to Consent to Medical Treatment." Hastings Center Report **36**(6): 25-34.

[5] Carnevale, F. A. (2004). Listening Authentically to Youthful Voices: A Conception of the Moral Agency of Children. Towards a Moral Horizon: Nursing Ethics for Leadership and Practice, 1st Ed. J. Storch. Toronto, Pearson Prentice Hall**:** 396-413.

[6] Bioethics Committee, Canadian Paediatric Society, (2004). "Treatment decisions regarding infants, children and adolescents." Paediatric Child Health **9**(2): 99-103. p. 101.

[7] Bioethics Committee, Canadian Paediatric Society, (2004). p. 99.

[8] (2009). *A.C. v. Manitoba (Director of Child and Family Services),* 2009 SCC 30, [2009] 2 S.C.R. 181, Supreme Court of Canada. [46].

remain in practice. For example, children’s autonomy is often and easily subverted in favour of protecting adult conceptions of their “best interests.”[9, 10] Confusion about the correlation between certain legal rights and the ethical obligations they help ensure, serve to discount an ethical duty to respect children’s autonomy, and children are often held to a higher standard than adults, when attempting to prove their competency.[11] If the philosophy expressed by pediatric medical guidelines and the Canadian legal system truly demonstrate a recognition of and appreciation for pediatric autonomy, what could explain why in practice, pediatric autonomy continues to be subverted by paternalistic practices?

Feminist bioethics proposes a possible answer. Along with the criticisms outlined above, feminists also assert that the traditional concept of autonomy focuses attention too narrowly on an individual patient’s ability to make a rational decision, while ignoring the context and social structure within which the patient is required to do so.[12] Feminists have recognized that this individualistic focus tends to obscure the role played by supportive or oppressive social conditions that can either foster or hinder a person’s ability to exercise their autonomy, and have developed a “relational” approach to autonomy, meant to respond to these shortcomings.

Relational autonomy situates autonomy within the broader social context in which it is exercised and legitimizes autonomy claims based on a more comprehensive account of agency, which implies taking into account the full

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[9] Carnevale, (2004)

[10] (2009) *A.C. v. Manitoba (Director of Child and Family Services)*

[11] Alderson, P., K. Sutcliffe, *et al*. (2006). "Children's Competence to Consent to Medical Treatment."

[12] Mackenzie, C. and N. Stoljar (2000). Relational autonomy : feminist perspectives on autonomy, agency, and the social self. New York, Oxford University Press.

impact of our embodied experience rather than merely one narrow aspect of it, i.e., rationality. Accordingly, a relational approach to autonomy is attentive to social forces at play that can foster or oppress an individual's ability to develop and exercise their autonomy.

In their introduction to, *Relational autonomy: feminist perspectives on autonomy, agency, and the social self,* editors Catroina MacKenzie and Natalie Stoljar explain that social forces can affect autonomy on three levels;

> The first level is that of the processes of formation of an agent's desires, beliefs, and emotional attitudes, including beliefs and attitudes about herself…The second level is that of the development of the competencies and capacities necessary for autonomy, including capacities for self-reflection, self-direction, and self-knowledge…The third level is that of an agent's ability to act on autonomous desires or to make autonomous choices. Autonomy can be impeded at this level not just by overt restrictions on agents' freedom but also by social norms, institutions, practices, and relationships that effectively limit the range of *significant* options available to them.[13]

It is my contention that despite the theoretical acceptance of pediatric autonomy, paternalistic practices that ignore children's moral agency, and their developing autonomy, continue to be legitimized and upheld as a result of subtle but oppressive social forces. The goal of my thesis is thus to adopt a feminist "relational" approach to autonomy, in order to investigate how social forces affect pediatric autonomy on all three of the levels described by MacKenzie and Stoljar. Given the theoretical commitment to respect for pediatric autonomy, oppressive social forces may be one of the last hurdles to overcome before pediatric patients enjoy true respect for their autonomy.

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[13] Mackenzie, C. and N. Stoljar (2000). p. 22.

Those who have never faced the unimaginable situation of having a seriously ill child, or who have never worked in pediatric health care, are often shocked at my assertion that children have an autonomy claim at all; therefore, in order to progress with my project, I will first need to provide a great deal of background information.

In Chapter 1, I provide a history of the discipline of bioethics and the traditional sociological view of children. Bioethics grew out of a particular historical and social context that sought to make medical ethics more secular, objective and rights-based.[14] As a result, patient autonomy came to be recognized as a cornerstone bioethical principle. While this empowered adult patients by giving them some control over their medical care, the traditional sociological view of children as vulnerable and passive, encouraged bioethical discourse and practice to focus on protecting children by deciding for them.

This chapter will establish that as new sociological understandings of children and their capabilities are introduced, bioethical discourse will need to evolve to better respect children's interests and to more accurately reflect their abilities and social standing. Furthermore, I suggest that the ease with which children's autonomy interests are subverted is at least partly due to bioethical discourse's reliance upon outdated theories and concepts about children.

In chapter 2, what differentiates feminist approaches to bioethics from traditional approaches will be explained. By conceiving of autonomy in terms of a scale of competencies, recognizing alternative perspectives and values, and

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[14] Belkin, G. and A. Brandt (2001). "Bioethics: Using Its Historical and Social Context." International Anesthesiology Clinics **39**(3): 1-11. p. 5.

focusing on social forces that can oppress the development and exercise of autonomy skills, feminists address important issues that are ignored on more traditional conceptions.[15, 16, 17] This chapter will examine feminist approaches to bioethics and apply them to the pediatric context in order to expose the ways in which traditional bioethics has underappreciated pediatric perspectives, skills and knowledge that contribute to their autonomy competency.

I believe that despite significant progress in theory, respect for pediatric autonomy still admits of important gaps in practice. I attribute these "gaps" to oppressive social forces that have not been thoroughly identified or examined. This chapter will establish why applying a relational approach to pediatric autonomy will be helpful in identifying areas for improvement.

Respect for autonomy in health care was founded primarily upon respect for the moral agency and dignity of persons, and in response to a particular social context. In Chapter 3, I will establish the moral status of children, and what rights and duties that status implies. In, "Listening Authentically to Youthful Voices," Franco Carnevale asserts that children are moral agents in their own right. This assertion however, remains disputed and Carnevale claims that "a significant body of literature has demonstrated that children are frequently exploited as moral

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[15] Tong, R. (1997). Feminist approaches to bioethics : theoretical reflections and practical applications. Boulder, Colorado. Westview Press.

[16] Wolf, S. M. (1996). Introduction: Gender and Feminism in Bioethics. Feminism and Bioethics: Beyond Reproduction. S. M. Wolf. New York, Oxford University Press.

[17] Sherwin, S. (1992). No Longer Patient: Feminist Ethics & Health Care. Philadelphia, Temple University Press.

objects; that is, they are regarded as means to the moral pursuits of the more powerful adults in their lives."[18]

Brennan and Noggle's article, "The Moral Status of Children: Children's Rights, Parents' Rights, and Family Justice," is an "attempt to provide a philosophical foundation for thinking about the moral status of children."[19] In it, Brennan and Noggle defend claims that they feel represent "widespread convictions about how we ought to treat children."[20] Although they argue for "equal moral consideration" for children, they also affirm that we are justified in treating children differently from adults, i.e. the "unequal treatment thesis." They reconcile these two claims, which appear inconsistent, by arguing that moral status in conferred not only by personhood, but also by certain roles, which require certain abilities or qualifications to fulfill. Children who cannot fulfill these roles can be denied the associated role-dependent rights, and therefore, can legitimately be treated differently from adults.

Since respect for autonomy is not absolute, but requires certain skills and competencies, I will describe the standards by which adult patients are judged to be competent to make health care decisions and present evidence that pediatric patients with illness experience can meet these requirements. This will confirm that the "equal moral consideration thesis" is not consistent with the "unequal treatment thesis" in the health care context.

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[18] Carnevale, (2004). p. 399.

[19] Brennan, S. and R. Noggle, (1997). "The Moral Status of Children: Children's Rights, Parents' Rights, and Family Justice." Social Theory & Practice **23**(1): 1-26. p. 1.

[20] Brennan, S. and R. Noggle, (1997). p. 1.

In order to illustrate how health care policy currently recognizes pediatric autonomy, I will briefly review the Canadian Paediatric Society's position statement which offers guidelines for involving children in health care decision-making and Canadian Health Law as it relates to children. However, as an example of the contradictions often encountered in practical attempts to respect pediatric autonomy, I will summarize the 2009 Supreme Court of Canada decision in, *A.C. v. Manitoba (Director of Child and Family Services)*. The Supreme Court decided to uphold a medical treatment order for the minor child A.C., in order to protect what the court assumed to be her "best interests." However, careful reading of the court's comments in not only the dissenting opinion but in the majority judgment as well reveals the clear tension between support for pediatric autonomy in theory versus respect for it in practice.

Finally, in Chapter 4 I will adopt a "relational" approach to autonomy to investigate how social forces affect a child's ability to develop and exercise autonomy. Children's rational and cognitive abilities are but one small part of the pediatric autonomy equation, their embodied experience is also shaped by social cues that adults are not even always aware they are sending and which can negatively influence a child's ability to exercise autonomy, despite significant cognitive capabilities. I will use a relational approach to analyze various studies that attempted to: identify aspects of communication that children find helpful or obstructive, to elicit the "voice" or perspectives of the child and to uncover parental perceptions of their role in medical decision-making on behalf of their children; this will illustrate how social forces can silence the pediatric voice and severely limit the child's ability to develop and exercise their autonomy.

Chapter 1: A History of the Concept of Autonomy, Pediatrics and the Discipline of Bioethics

Introduction:

It may seem strange to begin a discussion about pediatric autonomy with a lesson in history. However, it is my belief that by assessing the historical context from which the disciplines of pediatrics and bioethics grew, and from which the importance we place on patient autonomy evolved, we might uncover certain unhelpful historical assumptions still at play in modern discussions about pediatric autonomy. If this can be shown, and these assumptions overturned, bioethical discourse and practice in relation to children might find the impetus to evolve in response to more current ideas about children and their capacities and in light of their current social standing.

The word autonomy, in everyday language, usually implies self-determination. It is derived from the Greek words *autos* (self) and *nomos* (rule) and historically was used to refer to self-governing city states rather than individuals per se. Over the years, the concept of autonomy came to be individualized and to generally mean a person's individual right to decide the course of their life and to make decisions for themselves according to their own values, goals and priorities, without constraining, controlling or coercive influences.[21]

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[21] Beauchamp, T. and J. F. Childress (2009).

Respect for autonomy in biomedical contexts did not become a fundamental ethical principle until the late 1970's, following a series of highly publicized ethical scandals involving medical research, the development of powerful medical technologies, a social movement fighting for individual authority and civil rights, and some landmark court rulings that affirmed patients' rights to make decisions for themselves, which cemented respect for patient autonomy within bioethical discourse.

Children however, were left out of the move towards autonomy. Children were not represented in the social movements of that time, they enjoyed few legal rights, held inferior social standing, and in light of atrocious research abuses that had taken place involving children, they were perceived as inherently vulnerable and in need of protection. Furthermore, early conceptions of autonomy demanded rational, independent decision-making and children were assumed to lack the necessary cognitive capacities.

Although recognition and respect for pediatric autonomy has come a long way since the 1970's, gaps remain in practice. This chapter aims to offer a historical basis for those gaps and to illustrate that our bioethics in relation to children and their autonomy demands evolution in response to the current social context.

Medical Research and the Evolution of Bioethics:

The birth of modern pediatrics is historically tied to the medicalization of infant mortality at the turn of the century. Rampant infant mortality rates led to a new focus on identifying treatable causes of infant mortality for this previously inconsequential group.[22, 23] The urgency attributed to the need for medical research into this cause necessitated a source of available child research subjects.

> The first children chosen for use as experimental subjects were foundlings and orphans. Because nineteenth century infant mortality rates were so high, scientists felt a great need to study the reasons for childhood deaths. The subjects of study were quite naturally infants. Given the predominance of child labor at that time, researchers easily obtained experimental subjects for their studies. It was not until 1875 that an organization was established for the protection of children. Prior to that time, the Society for the Prevention of Cruelty to Animals was empowered by the courts to act in cases of cruelty to children.[24]

However, despite the intention to study childhood medical problems and to develop effective treatments and cures for their benefit, many orphaned and institutionalized children were used unconscionably and callously as human guinea pigs to that end.

> Prior to 1966, children were frequently subjects in research because they were convenient: researchers would often experiment on their children, servants, or slaves. Children could also be recruited from institutions. In 1914, Alfred Hess, the medical director of the Hebrew Infant Asylum in New York City, explained the scientific advantage of enrolling institutionalized children; it permitted "conditions which are insisted on in considering the course of experimental infection among laboratory animals, but which can rarely be controlled in a study of infections in man." Children were also "cheap" in the sense of non-valued; in fact, one researcher explained that he used child subjects because they were "cheaper than calves." In fact, Lederer and Grodin (1994) describe the role of children in medical research in the century prior to 1966 as largely one of child abuse.[25]

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[22] Markel, H. (1996). "Academic Pediatrics: The View from New York City a Century Ago." Academic Medicine **71**(2): 146-151.

[23] Carnevale, (2004).

[24] Konkle, B. (1974-1975). "Nielsen v. the Regents." Hastings Constitutional Law Quarterly **2**: 1151-1176. p. 1156

[25] Friedman-Ross, L. (2004). "Children in Medical Research balancing protection and access: has the pendulum swung too far?" Perspectives in Biology and Medicine **47**(4): 519-536. p. 520.

Clearly, the moral worth of these children was not recognized and their human rights were denied. The very fact that children were originally accorded protection under the Society for the Prevention of Cruelty to Animals speaks to the inferior social position they held at that time.

Although, children were not the only ones to suffer abuse at the hands of medical researchers, it was not until "research developed to the point that persons other than patients and foundlings were used as experimental subjects [that] the issue of consent became important."[26] Even then, the requirement for consent and the ethical issues inherent to experimentation on human subjects was addressed only sporadically.

The first Inkling of Autonomy:

The Nuremberg Code of 1947 was the first formal document to establish an ethical requirement to obtain informed consent from subjects participating in medical research or experimentation. The code was written in response to the Nuremberg trials in which a group of Nazi physicians who had subjected their unwilling captives, including children, to horrific forms of "medical" experimentation, were tried for crimes against humanity.

In their defense, the Nazi physicians argued: that the necessity of advancing medical knowledge that arose in the context of war justified their practices,[27] that the Allies had also undertaken medical experimentation in support

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[26] Konkle, (1974-1975). p. 1157.
[27] Konkle, (1974-1975). p. 1162.

of the war effort yet were not on trial, and that no formal international ethical guidelines for research with human subjects existed, so none had been breached.[28]

The trial judges recognized that the goals of medical experimentation could be at odds with an individual patient's best interests, and the need for some formal ethical guidelines. The resulting Nuremberg Code formalized ten ethical principles, the requirement of consent among them, to ensure protections for patients involved in medical experimentation and based on them, the Nazi physicians were found guilty. [29]

"The famous first principle of the Nuremberg Code – the voluntary consent of the human subject is absolutely essential- restricted experimentation to those individuals with the legal capacity to render consent."[30] Although the word "autonomy" did not appear in the language of the Nuremberg Code, the Code did insist that persons who consented had to be "so situated as to be able to exercise free power of choice…without the intervention of any element of force…" and had to have "sufficient knowledge and comprehension of the subject matter involved as to enable him to make an understanding and enlightened decision."[31] This language seems to indicate a concern for autonomy, even if the term itself is lacking. Since children were not considered capable of legal consent, the Nuremberg Code in effect aimed to protect children by excluding them from participation in research altogether.

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[28] Moreno, J.D., (2001). "Goodbye to All That: The End of Moderate Protectionism in Human Subjects Research." Hastings Center Report **31**(3): 9-17.

[29] Moreno, (2001).

[30] Lederer, S. E. (2003). "Children as Guinea Pigs: Historical Perspectives." Accountability in Research **10**: 1-16.

[31] Nuremberg Code as quoted in: Beauchamp, T. L. and J. F. Childress (1983). Principles of Biomedical Ethics, Second Edition. New York, Oxford University Press. p. 66.

Until this point in history, the beneficent nature of the doctor-patient relationship had been assumed to be enough to ensure that medical interventions were always in the best interests of the patient. Since the formulation of the Hippocratic Oath, estimated to have been written in the 4th century B.C.E., physicians were bound by the medical-ethical principles of beneficence, to do what is best, and non-maleficence, to do no harm, but the Oath made no mention of any requirement to respect patients' wishes, nor obtain consent.

> The paternalism inherent to the Oath of Hippocrates and its concentration on benefits to individual patients proved to be fit companions for American practitioners and their evolving sense of professionalism through the 18th, 19th, and early 20th centuries…Christian ethics and virtues were essentially synonymous with good medical ethics and high standards of professionalism. Other qualities important to ethical practice, ranking just below Christianity, were those of male gentility: "proper birth, sufficient wealth, unblemished character, adequate learning, and civic service." However, by 1900, a minority of physicians were advocating for stricter attention to applied scientific knowledge, and that technically proficient skills were just as important, if not more so, than religious beliefs, virtue-based codes, and physician status in larger community.[32]

In response to the Nuremberg Code, physicians bristled at the idea that their professionalism and personal ethics were not enough to ensure that patients were not abused. They balked at the idea that legitimate medical research might be hindered by this new consent requirement, stemming from what they saw as an unfair comparison to the extreme example of the Nazi experiments.[33] Therefore, the Nuremberg Code was not widely adopted in practice and researchers

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[32] Dell, M. L. and K. Kinlaw (2008). "Theory can be relevant: An Overview of Bioethics for the Practicing Child and Adolescent Psychiatrist," Child and Adolescent Psychiatric Clinics of North America, 17: 1-19.

[33] Moreno, (2001). p.12.

continued to use both children and adults as subjects in sometimes questionable medical experimentation.

It was not until a series of scandals involving medical research practices were publicly exposed and began to shake public faith in the medical establishment's altruism and ethics, that informed consent came to be understood as a duty doctors owed to their patients. Henry Beecher's article, "Ethics and Clinical Research," published in the *New England Journal of Medicine* in 1966, did more to make physicians question the prudence of allowing medical researchers to assess the ethics of their own research than had any formal ethical requirements or professional debate to date.

In his article, Beecher exposed 22 research studies, 4 of them involving children specifically, the results of which had also been published in upstanding medical journals, and which upon review, were each guilty of a serious disregard for basic human rights.[34]

> A long list of studies identified in anesthesiologist Henry Beecher's 1966 analysis in the *New England Journal of Medicine* epitomized the sense of a tragic failure of research medicine to respect basic human rights. Together, these revelations, and others like them, exposed a research culture in which the interests of subjects could be fundamentally disregarded in the name of science. Rising concern about research ethics also pointed to more fundamental questions about the character of medical authority within clinical medicine. More formalized expectations of informed consent and peer and bioethicist scrutiny of research translated into similar calls for rules and oversight of clinical practice. Informed consent soon became the most basic premise for both research and clinical care.[35]

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[34] Beecher, H. K. (1966). "Ethics and Clinical Research." The New England Journal of Medicine **274**(24): 1354-1360.

[35] Belkin, *et al.* (2001). p. 3.

One example Beecher used to illustrate unethical research practices was a study undertaken at the Willowbrook State School, an institution for intellectually handicapped children in Staten Island, New York. In the 1950's and 60's, physicians purposely infected children institutionalized there with Hepatitis, by feeding them extracts of stool from other infected patients. The purpose of the research was to study the progression of the disease when left untreated, and later to assess the promise of a new therapeutic intervention.

Another scandal, not addressed by Beecher but publicly exposed in 1972, was the Tuskegee Syphilis study which began in 1932. Over a forty year period, the study recruited 400 poor, African American men with Syphilis, into a program that researchers explained offered free treatment for "bad blood." In fact, the researchers withheld treatment, even when established antibiotic therapy became widely available in 1953, in order to study the progression of the disease. Public outcry over unethical medical research practices, and attempts to formally regulate research to protect subjects from this kind of abuse required,

> The development of new institutions and procedures for scrutinizing human subjects research. These efforts, in the form of government investigations and the creation or expansion of oversight rules and regulations, used, and in turn nurtured, a new kind of asserted expertise in bioethics upon which to shape and justify such rapidly expanding scrutiny."[36]

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[36] Belkin *et al.* (2001). p. 3.

The Effect of Social Pressures on the Development of Bioethics as a Discipline:

The discipline of biomedical ethics may have grown primarily from a need to protect human research subjects from abuse. However, bioethics today, and the importance placed on respect for autonomy, is the result of a combination of both the medical progress and public scandal stemming from such research, legal precedents, and social movements that occurred over the 1950's, 60's, and 70's.

Human medical experimentation led to a wide array of technological advances, which in turn led to the concentration of medical services into the hospital setting and the development of medical specialties and sub-specialties. These developments placed increased focus on technical knowledge and skills, somewhat lessening the focus on the virtuous character of physicians. Coupled with "the broader context of the rights-based movements for self-determination in the 1950s and 1960s [which included]…the civil rights movement, the rise of the new women's rights movement, and early patients' rights activities focused principally on psychiatric issues of civil commitment and the right to refuse treatment,"[37] these developments led to a new understanding of the patient as an active participant in her own health care, rather than a merely passive recipient.

Furthermore, a veritable explosion of impressive new medical technologies and therapies, developed from medical research, were being implemented at a fast past. For example, new technologies such as cardio-pulmonary resuscitation,

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[37] Belkin *et al.* (2001). p. 3-4.

artificial respirators and dialysis machines meant that for the first time ever, doctors were capable of prolonging the lives of critically, or even terminally ill patients. However, all of these technological advances brought with them new ethical dilemmas, the likes of which had never been seen, and for which the ethics of the day were inadequate.

> The emergence of a unique bioethics expertise needs to be seen within yet another, related context. Many of its leading figures in the late 1960's and early 1970's came from, and were responding to, perceived limitations of more theologically based approaches to ethics. At this time many of the ethical issues receiving heated debate involved issues of biology – contraception, abortion, population control, and genetics, issues tightly related to notion of sinfulness and that required reconsideration of the role of religious authority. Interest in creating a more secular and diverse political and ethical culture to take on these new biotechnological questions encouraged approaches to moral philosophy that could offer a solid ground of justification to replace religious faith within the bounds of its own reasoned logic and method.[38]

In order to do this, "the initial focus of bioethics was to define and defend a principle of the autonomy of the patient and his or her decisions and uniqueness that demanded respect that was more secular, objective and rights-based."[39] The ethical framework devised by the pioneers of this new discipline came to be known as "principlism" and represented a relatively small set of basic ethical commitments, the cornerstone of which was a respect for individual autonomy.

The burgeoning discipline of bioethics also coincided with the development of North American legal jurisprudence that began to uphold a patient's right to refuse medical care based on liberty rights such as bodily integrity, privacy rights, and in some cases religious rights.

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[38] Belkin *et al.* (2001). p. 4.
[39] Belkin *et al.* (2001). p. 5.

Legal Support for Respect for Autonomy:

In a 1973 *Rutgers Law Review*, Norman Cantor outlined many of the legal arguments that were being offered at that time to justify judicial intervention to secure lifesaving medical treatment. Treatment could be forced upon an individual when overriding public interests could be cited. The preservation of society, sanctity of life, public morals, protection of the individual against himself, and even protection of third parties - surviving adults, minor children, physicians and other patients - were all argued to be legitimate public interests that justified judicial intervention to force treatment.[40]

Disturbing practices in regards to medical experimentation also tended to be easily justified by appeals to the benefits of developing generalized medical knowledge that would benefit society at large, with little attention paid to the consequences suffered by the singular research subject. Evidence that this mindset remained entrenched in the minds of many researchers well into the 1970’s is offered in philosopher Hans Jonas’ 1974 essay, “Philosophical Reflections on Experimenting with Human Subjects,” in which he warned:

> We can never rest comfortably in the belief that the soil from which our satisfactions sprout is not watered with the blood of martyrs. But a troubled conscience compels us, the undeserving beneficiaries, to ask: Who is to be martyred? In the service of what cause and by whose choice? Not for a moment do I wish to suggest that medical experimentation on human subjects, sick or healthy, is to be likened to primeval human sacrifices. Yet something sacrificial is involved in the selective abrogation of personal inviolability and the ritualized exposure to gratuitous risk of health and life, justified by a presumed greater, social good.[41]

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[40] Cantor, N. L. (1973). "A Patient's Decision to Decline Life-Saving Medical Treatment: Bodily Integrity Versus the Preservation of Life." Rutgers Law Review **26**: p. 242-254.

[41] Jonas, H. (1974). Philosophical Reflections of Experimenting with Human Subjects. Philosophical Essays from Ancient Creed to Technological Man. Chigaco, The University of Chicago Press. p. 111.

It was the landmark case of Karen-Ann Quinlan that seemed to solidify, once and for all, a patient's right to determine what care they would accept. In 1976, 21 year old Karen Ann Quinlan was severely brain damaged after consuming a mixture of drugs and alcohol and losing consciousness. Left in a persistent vegetative state, and showing no signs of improvement, her parents asked that her artificial respirator be removed and that Karen be allowed to die. Her physicians refused based on the premise that this would be the equivalent of killing her.

The parents took their case to the New Jersey Supreme Court which upheld her father's petition. "The court posited that Karen, if competent, would be constitutionally entitled to resist life-sustaining medical intervention. Her entitlement flowed from the 14th Amendment to the U.S. Constitution and its protection of liberty."[42] Her father was granted permission to exercise this right on her behalf and Karen was removed from her artificial respirator but lived for several years before succumbing to pneumonia. Since Quinlan,

> State court decisions upholding a competent patient's liberty to reject life support have relied on both bodily integrity and patient autonomy – i.e., self-determination in deciding how and if to respond to a fatal affliction. The autonomy interest has prevailed even when the prospective bodily invasions have been rather slight, as in the case of refusal of a life-sustaining blood transfusion. These same decisions have considered and rejected possible governmental interests opposing the patient's prerogative. The cases acknowledge a legitimate governmental interest in promoting sanctity of human life, but they also tend to find that a patient's liberty interests (self-determination and bodily integrity) simply outweigh the state's abstract interest in sanctity of life.[43]

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[42] Cantor, N. L. (2001). "Twenty-Five Years After Quinlan: A Review of the Jurisprudence of Death and Dying." Journal of Law, Medicine and Ethics **29**: 182-196. p. 183.

[43] Cantor, (2001). p. 183-4.

The historical, social, and legal contexts outlined above explain why principlism eventually emerged as the preferred approach to bioethical analysis and discourse, and why respect for patient autonomy became a cornerstone of that approach.

The Introduction of Respect for Autonomy into Bioethical Discourse:

In 1979, authors Tom Beauchamp and James Childress wrote the first edition of *Principles of Biomedical Ethics*, in which the four main bioethical principles still in use today, were described: respect for patient autonomy, beneficence, nonmaleficence, and justice. The relative novelty of principlism as an ethical theory is evidenced in the preface to the book, where the authors explain that,

> This book offers a systematic analysis of the moral principles that should apply to biomedicine. Many books in the rapidly expanding field of biomedical ethics focus on a series of problems such as abortion, euthanasia, behavior control, research involving human subjects, and the distribution of health care. Rarely do these books concentrate on the principles that should apply to a wide range of biomedical problems…Only by examining moral principles and determining how they apply to cases and how they conflict can we bring order and coherence to the discussion of these problems."[44]

The value and importance placed on respect for individual autonomy in biomedical contexts today is often historically attributed to two important philosophers' works, Immanuel Kant's *Groundwork for a Metaphysics of Morals*, first published in 1785 and John Stuart Mill's *On Liberty*, written in 1859. Kant argued "that the incomparable dignity and unconditional value of human

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[44] (as quoted in) Beauchamp, T. L. and J. F. Childress (1983). p. ix.

autonomy is the necessary and sufficient condition of all morality."[45] From this, Kant derived his categorical imperative that we should treat people always as ends in themselves and never merely as means. Although Kant's call to respect the inherent value of human beings, grounded upon their capacity for self-direction and self-determination, helped establish the principle of autonomy's use in bioethics,

> Kant's theory renders autonomy something very different than writers in applied ethics mean in using the notion, although there are two conditions of overlapping agreement: (1) Kant argued that respect for autonomy flows from the recognition that all persons have unconditional worth, each having the capacity to determine his or her own moral destiny, (2) Kant argued that to violate a person's autonomy is to treat that person merely as a means, that is, in accordance with other's goals without regard to that person's own formulations of rules. These are the only fragments of Kant that have been appropriated.[46]

John Stuart Mill argued for respect for personal autonomy so as to keep in check the level of intervention that a State could impose upon its citizens. He argued that personal freedom should prevail as long as the exercise of that freedom did not cause harm to anyone else.

> The only purpose for which power can be rightfully exercised over any member of a civilized community, against his will, is to prevent harm to others. His own good, either physical or moral, is not sufficient warrant. He cannot rightfully be compelled to do or forbear because it will be better for him to do so, because it will make him happier, because, in the opinion of other, to do so would be wise or even right.[47]

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[45] Guyer, Paul, (2007) Kant's Groundwork for the Metaphysics of Morals, Continuum International Publishing Group: London, p. 1.

[46] Beauchamp, T. (2007). "History and Theory in "Applied Ethics"." Kennedy Institute for Ethics Journal **17**(1): p. 61.

[47] Mill, John Stuart, as quoted in: Mappes, T. A. and D. DeGrazia, (2001). Biomedical Ethics 5th Edition. Boston, McGraw Hill. p. 47.

However, Mill is careful to point out that this same opinion cannot be applied to children.

> This doctrine is meant to apply only to human beings in the maturity of their faculties. We are not speaking of children, or of young persons below the age which the law may fix as that of manhood or womanhood. Those who are still in a state to require being taken care of by others, must be protected against their own actions as well as external injury.[48]

In the context of a tendency to prioritize public interests over individual patients' interests in both medicine and research, these were fitting philosophies upon which to base respect for autonomy in health care.

The Social Perception of Children:

However, bioethics took a divergent view of how best to protect children. As adult patients were starting to be recognized as autonomous agents, those most capable of protecting themselves and standing up for their values, children were being painted as inherently vulnerable and in need of adult protection.

> The primary legal issue in the use of children as subjects concerns their presumed mental and emotional incapacity to understand the nature and purpose of the experimental procedure and protocol and to weigh the risks it may entail for them. Because of this immaturity, the common law generally declares minors (persons under 21 years of age) to be incapable of legally giving consent to a medical procedure or treatment to be performed upon them. The intent behind the law is to protect the minor from harm which may result from his own ignorance or rashness, and from situations where he cannot be expected to resist undue coercion or persuasion to give his consent.[49]

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[48] Mill, John Stuart, as quoted in: Mappes, T.A. and D. DeGrazia, (2001). p. 47.

[49] Curran, W. J. and H. K. Beecher (1969). "Experimentation in Children a Reexamination of Legal Ethical Priniciples." The Journal of the American Medical Association **10**(1): 77-83. p. 77.

Further evidence regarding how children were perceived at this time in history is offered in the following quotation taken from Paul Ramsey's, "The enforcement of morals: nontherapeutic research on children," which he wrote in response to Richard McCormick's "Proxy Consent in the Experimental Situation." Ramsey asserts that,

> A child is not a moral agent…Consent in behalf of a child is based simply upon the fact that the child "standing in need of therapy is a human being who is to be cared for by others [precisely because] he is incapable of caring for himself [i.e., precisely because he is not a moral agent]. His parents…are to see to it that the real human goods are protected in him." McCormick's fundamental mistake is that he treats the child as in some sense a moral agent; or – as I have stated the same point – he "treats a child as not a child," or (above) he treats the child morally as a small adult.[50]

Given this failure to view children as moral agents or to recognize that children can be capable of the mental and emotional maturity to participate in their health care, it is not surprising that children's capacity for autonomy was also denied.

The Concept of Autonomy:

Perhaps in light of its relative novelty, the concept of autonomy itself was highly scrutinized. Feminist authors in particular took issue with the concept's narrow individualized focus and idealized conception of how people make decisions. Although I highlighted the fact that feminists have been particularly critical of the traditional concept of autonomy in my introduction, and plan to use their criticisms in my argument in support of pediatric autonomy claims, this is

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[50] Ramsey, P. (1976). "The enforcement of morals: nontherapeutic research on children." Hastings Center Report **6**(4): 21-30. p. 25.

not to imply that feminists were willing to abandon the concept. In fact, feminist author Susan Sherwin clearly expresses what I believe is a widely held current philosophy that speaks to why patients are in fact those best-suited to make important health care decisions for themselves, and why paternalism should be avoided.

> Health care may involve such intimate and central aspects of a person's life – including, for example, matters such as health, illness, reproduction, death, dying, bodily integrity, nutrition, lifestyle, self-image, disability, sexuality, and psychological well-being – that it is difficult for anyone other than the patient to make choices that will be compatible with that patient's personal value system. Indeed, making such choices is often an act of self-discovery or self-definition and as such it requires the active involvement of the patient. Whenever, possible, then, these types of choices should be made by the person whose life is central to the treatment considered. [51]

In response to feminist criticisms, the concept of autonomy has actually evolved to be much more inclusive. This idea will be explored in the next two chapters.

Conclusion:

This chapter offered insight into the historical and social context from which the discipline of bioethics grew, and explained how respect for patient autonomy came to be introduced as one of its fundamental principles. These are important considerations for pediatric autonomy because,

> Bioethics is historically contingent, it reflected – and responded to – a series of specific contemporary critiques of biomedical practice and was fundamentally shaped by the social and political conventions of the time in which it emerged.

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[51] Sherwin, S., (2000). A Relational Approach to Autonomy in Health Care. Readings in Health Care Ethics. E. Boetzkes and W. Waluchow. New York, Broadview Press**:** 69-87. p. 70.

> Therefore, the bioethics that emerged in this period may no longer be a particularly good "fit" for the range of moral and ethical dilemmas currently confronting American medicine.[52]

While the goal of bioethics is to resolve ethical problems associated with the practice of medicine or biomedical research, it also fundamentally aims to uphold the dignity and human value of the patients it protects. Bioethical concerns led to the evolution of the adult patient's role in health care from mere passive recipient, to an active participant; the introduction of informed consent requirements and a growing concern for respect for patient autonomy empowered patients, allowing them input into the nature and course of their care.

On the contrary, bioethical discourse involving children conceptualized them as inherently vulnerable, passive and in need of adult protection. As such, children were generally excluded from any meaningful participation in their own health care, leaving all choices and decision-making up to their parents, and regulating the circumstances under which parental consent was valid to cases where the treatment or research was accepted to be in the child's best interests.

Of course, the bioethical atrocities involving children described above happened within a particular social context and in light of the inferior social standing attributed to children at that time. Thankfully, our social perception of children has evolved, and children now enjoy the same fundamental human rights as adults. Furthermore, significant strides have been made towards involving children in health care decision-making on their own behalf, and respecting their autonomy. However, the perception of children that remains prevalent in

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[52] Belkin *et al.* (2001). p. 9.

bioethical discourse has not evolved at the same pace as our social perception of children.

The "new sociology of childhood" views *childhood* as a social construction, one that "reflects the historical, culture, values and the power structure of the particular society in which it occurs."[53] Accordingly, the new sociology of childhood has led to a more modern view of children as competent, autonomous, and capable of their own particular form of social participation, setting itself apart from the historical image of children as inherently incompetent, vulnerable, and passive "adults in waiting."[54]

However, a tension between wanting to protect vulnerable children from harm, and wanting to treat them fairly and respectfully, remains. While at first glance, these two goals do not appear to conflict, upon deeper reflection, this tension becomes both obvious and difficult to resolve. Part of this tension may be attributable to the failure of bioethics to fully embrace "the new sociology of childhood."

> Philosophy, however abstract and analytical it is, can be only as sound as the social evidence and theories on which it relies. Bioethics is still dominated, though, by outdated Piagetian age-stage theories of child development that tend to emphasize children's ignorance, inexperience, and inability to make truly informed autonomous decisions, as if the mind and conscience grow as slowly as the body.[55]

This chapter established how and why autonomy came to be a fundamental principle of bioethics and highlighted the fact that the discipline of

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[53] King, M. (2007). "The Sociology of Childhood as Scientific Communication: Observation from a social systems perspective." Childhood **14**(2): 193-213. p.201.

[54] Reynaert, D., M. Bouverne-De Bie, *et al.* (2009). "A Review of Children's Rights Literature Since the Adoption of the United Nations Convention on the Rights of the Child." Childhood **16**(4): 518-534. p.520-1.

[55] Alderson *et al.* (2006). "Children's Competence to Consent to Medical Treatment." p. 25.

bioethics is normally responsive to social changes. I suggest that bioethical discourse in relation to children and their autonomy has failed to progress its theories and practice to reflect current perceptions of children, and their cognitive and autonomy capacities; this idea will be explored more fully in Chapter 3.

In the next chapter, the feminist approach to bioethics, feminist criticisms of the traditional concept of autonomy, and how their philosophical contributions in this area offer us a new perspective on children's illness experiences and their autonomy, will be explained.

Chapter 2: Feminist Approaches to Bioethics

Introduction:

It is commonly understood that "feminist work takes gender and sex as centrally important analytic categories, seeks to understand their operation in the world, and strives to change the distribution and use of power to stop the oppression of women."[56] However, perhaps surprisingly, feminist authors often radically disagree on issues, and there are few, if any, uniform "feminist" positions.

What unifies feminist work is that it denotes a particular approach to inquiry and analysis that I will adopt for my project.[57, 58] Therefore, my use of the general term "feminist," does not mean to imply that feminist theory can be summed up into a unified philosophy and applied homogeneously for the attainment of a particular outcome, nor to suggest that it does not admit of a significant diversity of views. My use of feminist analyses and authorship here is intended primarily to ensure that traditional concepts and methods are questioned, to illustrate how traditional bioethics frameworks fail to address pediatric perspectives and to broaden the analysis of pediatric autonomy to consider social forces at play.

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[56] Wolf, S.M., (1996). p. 8.

[57] Martin-Alcoff, L. and E. Feder-Kittay (2007). Defining Feminist Philosophy. The Blackwell Guide to Feminist Philosophy. L. Martin-Alcoff and E. Feder-Kittay. Malden, MA, Blackwell Publishing.

[58] Tong, (1997).

Although the concepts and methods of philosophical inquiry are intended to be objective, in reexamining traditional approaches, feminist work has uncovered a masculine gender bias in many of the concepts and methods used within a wide variety of disciplines. Feminist work has much to offer in terms of developing more balanced theories and methods because they have recognized that gender bias not only distorts the results of an analysis, but also which questions are asked, how the issue to be analyzed is framed, and even how the analysis is undertaken. Feminist analyses uncover the subtle ways in which certain groups dominate other groups, call into question underlying assumptions, and identify social forces that have served to legitimize oppressive structures and practices that disadvantage some groups.[59, 60]

In my introduction, I briefly touched on some general feminist criticisms of the traditional concept of autonomy. Feminist bioethical approaches to autonomy criticize the individualistic ideal of autonomy and instead: defend the importance and value of relationships, nurturance and care; analyze the relationship between the concept of autonomy and that of informed consent, in order to show that both idealize how patients make decisions, and therefore, cannot accommodate patients who do not meet that ideal; and criticize the concept's narrow focus on one particular patient's capacity to make one kind of decision, thereby obscuring the role of oppressive social forces that may hinder the patient's ability to exercise her autonomy.[61]

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[59] Lindemann, H. (2007). Feminist Bioethics: Where We've Been, Where We're Going. The Blackwell Guide to Feminist Philosophy. L. Martin-Alcoff and E. Feder-Kittay. Malden, MA, Blackwell Publishing.

[60] Sherwin, S., (1992)

[61] See for example, Sherwin, S. (2000).

In response to these shortcomings, feminists have developed what they call a *relational* approach to autonomy. As explained in the introduction, *relational autonomy* situates autonomy within the broader social context in which it is exercised and legitimizes autonomy claims based on a more comprehensive account of agency, which implies taking into account the full impact of our embodied experience rather than merely one narrow aspect of it, i.e., rationality.

Feminist philosophers are very concerned with identifying these social forces in order to overcome any oppression that results from them. However, the term "oppression" might initially appear ill-suited for use in discussions about pediatric autonomy. Since it is expected that children will require substantial adult guidance to survive and flourish, it may seem inconsistent to claim that parental authority could actually be oppressive; however, I believe the term to be appropriate and justified in this context.

Traditional bioethical discourse involving restraints on patients' autonomy usually employs the term *paternalism*. In her book, *No Longer Patient: Feminist Ethics & Health Care*, Susan Sherwin explains that,

> In medical contexts the term "paternalism" refers to the widespread practice in which physicians make decisions on behalf of their patients, without the full understanding or consent of the patient. To qualify as paternalism, the basis of the decision must be the patient's well-being; thus it is distinguished from actions the doctor might take out of self-interest. Because paternalism aims for the patient's good, it is recognized as well-intended action, but its actual achievement in bringing about the best consequences is in doubt, because it is the physician's – rather than the patient's – perception of the patient's good that is decisive.[62]

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[62] Sherwin, S. (1992). p. 138.

Given this definition, *paternalism* might seem like a more appropriate term to use in regards to parental restraint on children and their autonomy. After all, parents and physicians usually make health care decisions on behalf of children with regard to their best interests. However, Carnevale points out that "although parents are commonly the most appropriate advocates for a child's interests, the child's interests are intertwined with the parents' self-interests."[63]

> Although an ill child is surrounded by a variety of adult moral agents claiming to advocate for the child's best interests, these adults are also involved in pursuing their own interests. Given the significant power imbalance between these adult-centered agents and the largely silent, morally subordinated children, the latter run significant risk of moral objectification.[64]

Therefore, despite the child's best interests being cited as the basis for most health care decisions, it is obvious that parental self-interests are also at play, although the two are not necessarily inconsistent. Furthermore, "protection" of the best interests of children that leads to their moral objectification, seems to go beyond well-intentioned paternalism and merit being called *oppressive*.

In the biomedical context, Sherwin appeals to Marilyn Frye's definition of oppression as:

> An interlocking series of restrictions and barriers that reduce the options available to people on the basis of their membership in a group. Oppression is often insidious, because the individual practices that make up the system of barriers may look innocent when examined on their own; their role as restraints may be easily obscured. As Frye notes, however, when the various oppressive practices are seen as an interwoven set of institutionalized norms, the pattern of restriction becomes clear.[65]

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[63] Carnevale, (2004). P. 400.
[64] Carnevale, (2004). P. 400.
[65] Sherwin, (1992). p. 13.

Since the goal of my thesis is to adopt a relational approach to autonomy in order to investigate how social forces affect pediatric autonomy on different levels, I plan to uncover and analyze the effects of exactly these kinds of "interwoven institutionalized norms."

To focus on *paternalistic* practices, undertaken by one physician or set of parents on behalf of one child patient, might invite the same kind of criticism as the over-individualistic concept of autonomy. By focusing too narrowly on one particular patient's ability to make one particular decision, the traditional concept of autonomy has ignored the social forces at play that support or frustrate the patient's ability to do so.

By the same token, to focus on *paternalistic* practices here might also obscure the broader, more structured, more insidious social forces at play that hinder the development and exercise of autonomy for children as a group. Since oppression is particular to groups, *oppression* truly seems to be the most appropriate term to use in regards to the socially mediated suppression of pediatric autonomy that I will reveal in Chapter 4; therefore, I will continue to use the term.

To my knowledge, no one has used a feminist approach to systematically examine oppressive social forces that may be responsible for the ease with which pediatric autonomy can be subverted, although several authors who are supportive of pediatric autonomy echo feminist concerns in their work.

Before I can undertake this project, I first need to demonstrate that the feminist approach to bioethics is well-suited to this task. The aim of this chapter therefore, is to introduce the feminist approach to bioethics, and analyze it in respect to pediatric autonomy. In order to do this, I will first identify what differentiates the feminist approach to bioethics from more traditional approaches and highlight how the feminist approach to bioethical discourse might offer innovative ways to think about the specific example of pediatric autonomy on three important aspects. Finally, I will introduce the relational approach to autonomy devised by feminists to identify and overcome these problems, and describe how such an approach unearths a new area of inquiry that could lead to important progress in the area of pediatric autonomy.

Feminist Bioethics:

Feminist bioethics differentiates itself from more traditional bioethical approaches in several ways. Like any feminist undertaking, feminist bioethics insists that bioethical analysis requires attention to gender and seeks to uncover and overcome oppressive structures within bioethical discourse and practice that harm women and other disadvantaged groups.

In her introduction to the anthology *Feminism & Bioethics: Beyond Reproduction*, editor Susan Wolf argues that a feminist bioethics is different from traditional bioethical theories and frameworks in that "its subjects, epistemology, and analysis would all be different."[66] Rosemarie Tong offers a slightly different summary of what she feels feminist bioethics has to offer traditional or non-feminist approaches in the epilogue of her book, *Feminist Approaches to Bioethics*. Tong explains that asking questions about the role of gender in health care offers: "opportunities for conceptual reinterpretations and terminological

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[66] Wolf, (1996). p. 22.

revision; the possibility that an ontology of connectedness, of autokoenomy,[67] as opposed to one of separateness, of autonomy, better supports the practice of medicine; an epistemology of perspective, of *positionality*, as opposed to an epistemology of certitude, of Archimedean point;" and "an ethics of care combined with an ethics of power."[68]

I will examine how an ethics of care and attention to patient perspectives, bioethics epistemology, and relevant conceptual reinterpretations are generally addressed by feminist authors and relate these issues to the topic of pediatric autonomy. My goal is simply to illustrate that the traditional bioethics approach by which we analyze autonomy, fails to fully recognize the pediatric perspective and therefore, fails to overcome important biases that maintain the exclusion of children from the autonomy debate.

Feminist bioethics pays particular attention to the alternate views, particular circumstances and the lived experiences of patients that have been underappreciated in traditional bioethics. Gender dynamics that have helped frame issues, assign roles, and influenced practices within biomedical contexts in ways harmful to any oppressed group, need to be recognized, analyzed and reformed so as to better respect the interests, perspectives and values of individuals belonging to these groups. Therefore, a feminist approach to bioethics is well-suited to establishing respect for children's interests, perspectives and values as well.

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[67] Rather than self-rule, autokoenomy refers to rule by community.
[68] Tong, R. (1997). p. 243-246.

Feminist Ethics:

Feminist bioethics, building on the ideas and values found in feminist ethics and moral philosophy, analyzes bioethical issues according to a new moral framework. Feminists criticized traditional moral theories in general, for being based upon abstract, rational, so-called *universal* principles that fail to recognize that our social natures and our emotional bonds contextualize every ethical quandary, making reliance upon rights and principles insufficient.[69]

They have also criticized traditional approaches to moral philosophy for either failing to recognize that legitimate alternate systems of values, priorities and intuitions exist, or for assuming that they are less sound and even autonomy-reducing. Something important is being left out, they argue, when we construct our ethics upon a framework based on what they understand to be primarily masculine values that take reason, rights, rules and hierarchies to be the ultimate guide to morality.

General feminist criticisms of traditional moral theories led to the development of an alternate "feminist" ethics, one more attuned and responsive to the role and importance of relationships and emotional bonds in our moral theorizing. One of the most important contributions to feminist ethics in this regard was made by Carol Gilligan, a psychologist studying moral development, whose work seemed to show that women's moral perspectives differed from men's in important ways.

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[69] Sherwin, S. (1992).

Gilligan's book, *In a Different Voice*, was written in response to "the recurrent problems in interpreting women's development and to connect these problems to the repeated exclusion of women from the critical theory-building studies of psychological research."[70] Gilligan showed that women undertook moral reasoning more attuned to the context of the situation than rights-based approaches. She postulated the existence of so-called feminine values, and argued that women's moral decisions were often motivated by a desire to preserve or honour important personal relationships.

Although there is considerable controversy over whether a system of values can be categorized as masculine or feminine, Gilligan argued that,

> The psychology of women that has consistently been described as distinctive in its greater orientation toward relationships and interdependence implies a more contextual mode of judgment and a different moral understanding. Given the differences in women's conceptions of self and morality, women bring to the life cycle a different point of view and order human experience in terms of different priorities.[71]

Far from being inferior, Gilligan argued that women's moral perspective was actually more comprehensive and indeed, equally valid and worthy of respect.

> The disparity between women's experience and the representation of human development, noted throughout the psychological literature, has generally been seen to signify a problem in women's development. Instead, the failure of women to fit existing models of human growth may point to a problem in the representation, a limitation in the conception of human condition, an omission of certain truths about life.[72]

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[70] Gilligan, C. (1993). In a Different Voice. Cambridge, Mass., Harvard University Press. p. 1.

[71] Gilligan, (1993). p. 22.

[72] Gilligan, (1993). p. 1-2.

The subsequent development of what has come to be known as “Feminist” or “Care” Ethics is based on the new perspective offered by Gilligan’s work. Rather than a rights-based ethics, relying on rules, laws and hierarchies to objectively determine the most ethical course of action, care ethics denotes an approach that is sensitive to the unique contextual dimensions of every ethical dilemma and encourages consideration of the responsibility we owe to others due to the nature of our relationship with them, and a commitment to care for, and not hurt others. Stemming from these developments, feminists working in the domain of moral philosophy have worked to:

> Uncover gender bias in traditional philosophical approaches; to challenge some of the linchpins of those approaches, such as impartiality and universalizability; to question the adequacy of morality built on deduction from abstract principles with too little attention paid to particulars, context, and relationships; to describe different ways of analyzing and responding to moral problems and debate their connection to gender; to articulate and debate an ethics of care specifically and show what relationship it might have to an ethics of justice or rights; to challenge the traditional centrality of a liberal individualism that prizes autonomy and devalues interdependency; and to revive attention to the role of the emotions and virtues in moral life.[73]

While principlism is an attempt to define generalizable and universal principles via which bioethical analysis should proceed, feminist bioethics, like feminist ethics in general, is much more attuned to the importance of context and the circumstances particular to any given patient. In fact, a feminist bioethics recognizes the importance of personal relationships, the lived experiences, and the priorities, values and perspectives of the patient and how they all contribute to their moral reasoning.

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[73] Wolf, (1996). p. 9.

Although these important aspects of moral reasoning are harder to appreciate on a traditional framework that seeks to universalize and generalize a set of ethical principles applicable to all, a willingness to meaningfully include children and their views in bioethical discussion would send a strong social message to those children that they are important participants in their health care team and would potentially help foster certain skills necessary for the development of their autonomy.

Feminist Epistemology:

Another differentiation between feminist and traditional approaches to bioethics exists in regards to epistemology, i.e. the study or a theory of the nature and grounds of knowledge especially with reference to its limits and validity.[74] Although Wolf admits that there is perhaps no explicit bioethical epistemology, she points out that traditional bioethical discourse is most often undertaken by "experts," physicians, researchers, and bioethicists, on behalf of patients, without fully including those patients in the ethical discourse. Alternatively, "feminist epistemologies investigate the relationship between power, gender, and the means of generating authoritative knowledge."[75]

One particular example of a feminist epistemology is *standpoint theory*, a general approach that recognizes that any theory is affected by the standpoint from which it is developed and applied. A feminist bioethics would be sensitive to the diverse array of viewpoints that stakeholders subject to the outcome of

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[74] epistemology. (2010). In *Merriam-Webster Online Dictionary*. Retrieved May 13, 2010, from http://www.merriam-webster.com/dictionary/epistemology.

[75] Wolf, (1996). p. 25.

bioethical debate, hold. As such, it would encourage a more inclusive framework through which bioethical epistemologies come to be developed.

> Instead of persistently analyzing bioethics problems from the physician's or scientist's vantage point by asking what the doctor or scientist should do, we would at least as energetically view bioethics problems from the standpoint of the patient, subject, or citizenry. We would ensure their participation in the disciplinary dialogue.[76]

Feminist author Diana Tietjens-Meyers recognizes that there are several dimensions of selfhood that contribute to our sense of identity and capacity for autonomous action, and questions the traditional concentration on the unitary-self; "the independent, self-monitoring, self-controlling self that has been pivotal to autonomy theory…[as] the seat of rationality and thus rational deliberation and choice."[77]

> As a first step toward persuading you that conduct stemming from the self-as-social, the self-as-relational, the self-as-divided, or the self-as-embodied can be autonomous, I urge that attending to these dimensions of selfhood brings to light some neglected agentic skills. Moreover, I urge that these skills endow people with forms of practical intelligence that can be seen to facilitate self-discovery, self-definition and self-direction. If this is so, it seems to me that we cannot dismiss the possibility that the self-as-unitary is not the preeminent arbiter of autonomy.[78]

Although not arguing in relation to biomedical contexts, her assertion that: other dimensions of selfhood such as the self-as-relational and the self-as-embodied can provide us with important practical knowledge that can contribute to autonomy, is particularly relevant to the question of bioethical epistemology in

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[76] Wolf, (1996). p. 26.

[77] Tietjens-Meyers, D. (2005). Decentralizing Autonomy Five Faces of Selfhood. Autonomy and the Challenges to Liberalism. J. Christman and J. Anderson. Cambridge, Cambridge University Press**:** 27-55. p. 29.

[78] Tietjens-Meyers, (2005). p. 36.

pediatric autonomy. Traditional bioethics has disregarded the practical knowledge that children gain through embodied illness experience as a legitimate source of relevant knowledge, and has been slow to recognize its contribution to the development of autonomy.

Although it has been established that illness experience fosters complex practical knowledge of illness and treatment in children,[79, 80] traditional approaches have focused on children's abilities to understand complex biological or scientific conceptions. In the next chapter, I will provide evidence that demonstrates that children can develop complex understandings about illness and medical treatment if they have first hand illness experience and that this is not strictly correlated to their age. A feminist approach to bioethical epistemology would help ensure that a child's practical knowledge stemming from her embodied illness experience would be recognized and legitimized.

Feminist Criticisms of the Traditional Concept of Autonomy:

Lastly, as an example of Rosemarie Tong's suggestion that gender analysis in bioethics offers, "opportunities for conceptual reinterpretation and terminological revision,"[81] I want to examine feminist criticisms of the traditional concept of autonomy.

Fundamentally, all the feminist criticisms of autonomy stem from the traditional concept's individualistic focus. Since the very concept of autonomy speaks to an individual's capacity for self-determination, it may seem odd to

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[79] Alderson *et al.* (2006). "Children's Competence to Consent to Medical Treatment."
[80] Bluebond-Langner, (1978)
[81] Tong, (1997). p. 244.

attack it on that basis. However, Susan Dodds neatly summarizes how the individualistic approach to autonomy is problematic in several ways.

> The conception of autonomy used in bioethics is rationalistic, atomistic, and individualistic. It assumes something like an atomistic individual, making a choice wholly for herself or himself. It assumes that, paradigmatically, individuals are equally rational and able to reflect on complicated choices once given adequate information, [and] it ignores the social circumstances and power relations that affect choice contexts.[82]

I will examine each of these criticisms in turn and illustrate how the perceptions about autonomy that these criticisms attack, have helped to exclude children from the autonomy debate.

Feminists have criticized autonomy as an idealized masculine character trait that is ill-suited to recognize the truly social nature of people. The traditional concept of autonomy they argue, focuses too much on individuality and independent, self-interested decision-making, and therefore fails to recognize the importance of relationships, interdependence and social embeddedness.

While these aspects of our social natures have been embraced by feminists, they have often been unfairly understood as autonomy-reducing on the traditional framework. Given the prevalence and primacy of the concept of autonomy in bioethics discourse, those who fail to meet the traditional idealized standard of autonomy have been powerfully affected.

> Feminists…have criticized liberal individualism on several scores. By depicting the moral community as a set of atomistic and self-serving individuals, it strips away relationships that are morally central. This not only is impoverished, but may also be harmful, because it encourages disregard of those bonds. It is also inaccurate; developing children as well as full-grown adults are profoundly interdependent.[83]

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[82] Dodds, Susan. (2000) Choice and Control in Feminist Bioethics. Relational Autonomy Feminist Perspectives on Autonomy, Agency, and the Social Self. Ed. Catroina MacKenzie & Natalie Stoljar. New York: Oxford University Press: 213-35. p. 216.

[83] Wolf, (1996). p. 16.

Clearly, young children who are in the process of developing their concept of self and who may have little experience making decisions at all, cannot be relied upon to make completely independent decisions. This would not only be unwise, it would actually be burdensome to the children. However, a child's desire for parental input would not necessarily have to be considered autonomy reducing on the feminist conception.

The second criticism raised by Dodds above, is that the traditional concept of autonomy "assumes that, paradigmatically, individuals are equally rational and able to reflect on complicated choices once given adequate information." In "A Relational Approach to Autonomy in Health Care," Susan Sherwin offers an excellent explanation as to why this is highly problematic.

Sherwin explains that in order to be considered autonomous in the traditional sense, a patient must have all the information needed to make a decision, be able to understand it, be rational, i.e. competent to make a decision, be capable of choosing among available options, and be free from coercion. However, she also points out that "each of these conditions is more problematic than is generally recognized."[84]

Perhaps of greatest concern is that,

> The competency criterion threatens to exclude people who are oppressed from the scope of autonomy provisions altogether. This is because competency is often equated with being rational, yet the rationality of women and members of other oppressed groups is frequently denied.[85]

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[84] Sherwin, (2000). p. 73.

[85] Sherwin, (2000). p. 73.

As stated above, feminists have accused traditional bioethics of ignoring or belittling alternate perspectives, in particular, ones that prioritize emotional bonds and personal relationships instead of single-minded rationality. Children are one such example of a group whose rationality has historically been completely denied and that continues to be questioned. In reference to a study on children's ability to manage their diabetes, Alderson suggests that,

> Children's moral agency may not be recognized; their complicated consent may be underestimated as compliance; their sometimes reasoned "refusal" (such as if they decide it is occasionally more important for their social health to join in their friends' activities than to adhere strictly to the regimen proscribed for their physiological health) may be dismissed as foolish resistance, even though adults frequently make such lifestyle choices. While children may be blamed for poor glycemic control, their hard-won success may be attributed to the adults who care for them…Adults can make any decision for themselves, but an "enlightened" decision made for or by children has to demonstrably serve the child's welfare or best interests. [86]

Sherwin cautions that this tendency to presume the incompetency of members belonging to oppressed groups highlights the need for health care providers to become more attuned to how oppressive stereotypes may obscure a patient's rationality and capacities.

Secondly, in order to be autonomous, patients must have the information needed to make a decision, be able to understand it, and then be able to make a choice among available options. However, any determinations about what information is relevant to the decision at hand is usually made by a physician, who rarely shares the same social, economic and educational status of their patients. This gap in position can lead to the omission of important information

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[86] Alderson *et al.* (2006). "Children's Competence to Consent to Medical Treatment" p. 30.

that the patient might need. For example, a physician might assume that some particular information is common knowledge. However, her less well-educated patient does not share the same knowledge base. Worse yet, the physician might assume that an uneducated patient is incapable of understanding some of the complex information she would need, and decide not to share it, or share it without ensuring that the patient has the necessary background information to understand it.

Lastly, Sherwin explains that how the physician understands the medical issues and the patient's needs might also mean that only certain kinds of options are generated, none of which may be really satisfactory to a person in the patient's social or economic position. This individualistic concept of autonomy that concerns itself only with an individual patient's ability to make a particular decision makes it difficult to appreciate how a patient's social status and life circumstances might have a coercive affect by limiting what choices are realistically available to them.

Sherwin points out that most patients, when confronted with illness and suddenly reliant upon physicians who enjoy greater affluence and social power, suffer some loss to their autonomy.

> The tendency of illness to undermine patients' autonomy is especially threatening when the patients in question face other powerful barriers to the exercise of their autonomy, as do members of groups subject to systemic discrimination on the basis of gender, race, class, disability, age, sexual preference, or any other such feature.[87]

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[87] Sherwin, (2000). p. 71.

However, the issues described by Sherwin above, that speak to the difficulties in assuming all patients share the same capacity for decision-making as long as the appropriate information is shared, also highlights the insufficiency of mere informed consent to ensure meaningful respect for patient autonomy. Susan Dodds points out that the relationship between informed consent and patient autonomy as it is currently understood,

> Seriously constrains how we may conceptualize those who are not fully autonomous and how they are treated as a result. First, in this conception of autonomy, it is unclear how health-care workers ought to treat those who have some degree of autonomy but lack *full* autonomy. In practice those people whose capacity for choice might not be thought *fully* autonomous…may be treated in one of two unacceptable ways. On the one hand, because autonomy is identified with informed consent, if a person in this situation is given adequate information and makes a choice that appears to reflect her or his stable preferences, that choice will be treated as autonomous, even if the person has failed to understand or retain salient features of the information required for a genuinely autonomous choice. Alternatively, the person might display some signs of incompetence…and thus have her or his authority to make self-determining decisions removed. In this latter case, even if the person has the capacity to make a specific health-care decision, her or his claim to make autonomous choices is undermined…This lack of a middle ground, of an awareness that the capacity to make health-care decisions may admit of degrees, is one effect of the identification of autonomy with informed consent." [88]

Perhaps the greatest shortcoming of the traditional concept of autonomy is that by focusing on an individual's capacity for autonomous action, the role played by supportive or oppressive social conditions that foster or hinder autonomy are obscured. Those who fail to act autonomously or who cannot meet the requirements to be considered autonomous are seen as personally responsible. One may lack intelligence or competence, or allow oneself to be coerced by

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[88] Dodds, (2000). p. 217.

others, but these are understood to be regrettable personal shortcomings, rather than the results of socially mediated forms of oppression or disadvantage.

> This familiar sort of thinking tends to interfere with people's ability to see the importance of supportive social conditions for fostering autonomous action. By focusing instead on the injustice that is associated with oppression, feminism helps us to recognize that autonomy is best achieved where the social conditions that support it are in place. Hence, it provides us with an alternative perspective for understanding a socially grounded notion of autonomy.[89]

Relational Autonomy:

Feminists have developed an alternate, *relational* approach to autonomy "that recognizes the importance of social forces in shaping each person's identity, development, and aspirations."[90] A wide variety of feminist authors have responded to different aspects of these criticisms on different levels. Although they all adopt a relational approach which generally situates autonomy within the broader social context in which it is exercised, this does not necessarily denote a particular, or strictly defined concept of autonomy. Catriona MacKenzie and Natalie Stoljar explain that;

> The term "relational autonomy," as we understand it, does not refer to a single unified conception of autonomy but is rather an umbrella term, designating a range of related perspectives. These perspectives are premised on a shared conviction, the conviction that persons are socially embedded and that agents' identities are formed within the context of social relationships and shaped by a complex of intersecting social determinants, such as race, class, gender, and ethnicity. Thus the focus of relational approaches is to analyze the implications of the intersubjective and social dimensions of selfhood and identity for conceptions of individual autonomy and moral and political agency.[91]

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[89] Sherwin, (2000). p. 73.

[90] Sherwin, (2000). p. 78.

[91] MacKenzie, C., & N. Stoljar, (2000). p. 4.

For example, feminist author, Diana Meyers, developed her theory of *autonomy competency* which reconceptualized autonomy as a set of skills that, when exercised, lead to the development of an integrated concept of self. Her "theory of autonomy competency is motivated by a concern both to explain the autonomy-impairing effects of oppressive socialization and to develop a theory that is able to explain how agents who are subject to oppressive social circumstances may nevertheless be partially autonomous, or autonomous in certain domains of their lives but not in others."[92]

> She argues that autonomy is a competency comprising a cluster of different skills and capacities, in particular skills of self-discovery, self-direction, and self-definition, all of which involve reflection. Autonomy involves the capacity to exercise these skills to achieve an integrated but dynamic self…Meyers account is explicitly relational in that she argues that autonomy competency can be developed only in the context of social relationships, practices, and institutions.[93]

The idea that autonomy competency implies a range of skills and opportunities and admits of degrees seems to have been widely adopted in current discussions about pediatric autonomy. In Chapter 3, I will provide evidence that both Canadian pediatric medical guidelines and Canadian common law is it pertains to children and health care, reflect Meyers' basic premise that autonomy is comprised of degrees and should be respected according to its level of development.

Building on Meyers' work, the relational approach conceives of autonomy as a skill to be developed; "women and members of other oppressed groups can be helped to increase their autonomy skills by being offered more opportunities to

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[92] Mackenzie, C., & N. Stoljar, (2000). p. 17-18.

[93] MacKenzie, C., & N. Stoljar, (2000). p. 17.

exercise those skills and a supportive climate for practicing them."[94] Furthermore, feminist authors recognize that oppression tends to become internalized in its victims. "Socially constructed stereotypes can reduce both society's and the agent's sense of that person's ability to act autonomously. Relational theory allows us to recognize how such diminished expectations readily become translated into diminished capacities."[95]

My goal therefore, is to analyze how a relational approach to pediatric autonomy could offer the pediatric population more meaningful participation in their health care decision-making by uncovering oppressive social roles, structures and health care practices that hinder their attempts to have their autonomy recognized.

Conclusion:

Feminist bioethics champions respect for alternate perspectives and epistemologies in bioethical discourse, and have criticized the individualized traditional concept of autonomy in ways that also happen to be particularly relevant to children. In answer to these criticisms, feminists have devised a relational approach to autonomy that takes into consideration social conditions that may thwart an individual's attempt to exercise their autonomy, and seeks to overcome them.

Due in part to the criticisms put forth by feminist bioethics, the concept of autonomy has become more inclusive. Children have been studied to ascertain

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[94] Sherwin, (2000) p. 79.
[95] Sherwin, (2000) p. 79.

their reasoning capacities and their ability to understand complex information. However, while these assessments show that children are more capable of autonomy than previously thought, few authors move beyond the focus of pediatric capabilities to analyze how children may be hindered from developing and exercising their autonomy by the social context in which they must exercise it.

In the next chapter, I will argue that children deserve equal moral consideration in terms of respect for their autonomy, establish that children are capable of meeting the requirements to be considered competent and to act autonomously, but show that their autonomy is often not respected, and suggest that oppressive social forces are partly responsible for these findings.

Like the concept of autonomy in bioethics, the moral agency of children itself is a relatively new concept; it often takes a back seat in bioethical discussion, so that the more comfortable situation of having proxy decision-makers ensure that children's best interests are protected, can take precedence. Therefore, in the first section of the next chapter, I will review what Brennan and Noggle present as two "widespread convictions" about the moral status of children. They argue that although children merit equal moral consideration, their immaturity justifies their unequal treatment in terms of general public policy.

I will argue that children with illness experience can be capable of a level of competency that rivals adults and that when this is shown to be the case, it should allow them to make their own health care decisions; this repudiates the conventional reliance upon arbitrary age limits. By so doing, I overcome the basis for Brennan and Noggle’s “unequal treatment thesis,” and confirm that the health care context is one example in which inequalities in treatment are not justified.

Once it has been established that: children are moral agents who merit equal moral consideration of their autonomy claims, that they are capable of the mental competency required to have their autonomy respected and that medical guidelines and Canadian law recognize these assertions, then only the question remains: what can possibly explain why pediatric autonomy claims continue to be denied or subverted in favour of other interests? A relational approach that seeks to uncover subtle oppressive forces may offer the best answer to this question.

Chapter 3: Current Theory and Practice in Pediatric Autonomy

Introduction:

Establishing the moral status of children is an important first step in establishing that we owe children certain rights and duties in the context of health care. While this may seem like an obvious assertion, the moral status of children, like the concept of respect for patient autonomy, is also a relatively novel idea as evidenced by the historical traditions outlined in Chapter 1.

In "Listening Authentically to Youthful Voices," Franco Carnevale asserts that, "children should be regarded as moral subjects – agents who are likely capable of moral experience." However, he goes on to explain that "a significant body of literature has demonstrated that children are frequently exploited as moral objects; that is, they are regarded as means to the moral pursuits of the more powerful adults in their lives."[96] Carnevale explains that, "given the significant power imbalance between these adult-centered agents and the largely silent, morally subordinated children, the latter run a significant risk of moral objectification."

In "The Moral Status of Children: Children's Rights, Parents' Rights, and Family Justice," Samantha Brennan and Robert Noggle "attempt to provide a philosophical foundation for thinking about the moral status of children."[97] They propose a rights-based theory that honours some common sense claims that

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[96] Carnevale, (2004). p. 399.

[97] Brennan, S. and R. Noggle. (1997). p. 1

represent “widespread convictions about how we ought to treat children.”[98] The first two claims are particularly relevant to establishing the moral status of children, so I will examine them in particular. However, Brennan and Noggle admit that together, they appear to be inconsistent.

> We think that any acceptable theory of the moral status of children must be compatible with [these] claims: that children deserve the same moral consideration as adults [the equal moral consideration thesis], [and] that they can nevertheless be treated differently from adults [the unequal treatment thesis].[99]

In the next section, I will first explain Brennan and Noggle’s argument that certain rights are “role-dependent;” therefore, children can be justifiably denied certain rights if they cannot fulfill the associated roles.

As discussed in the introduction, the right to respect for one’s autonomy is contingent upon the patient’s demonstration of certain cognitive and rational capacities. In order to prove that the “equal moral consideration thesis’ and the “unequal treatment thesis” are inconsistent in the context of health care, I will describe the standards by which adult patients are judged to be competent, explore Canadian health law as it applies to children, and provide evidence that pediatric patients can be capable of meeting these standards and of being considered competent under the law.

Furthermore, I will bolster Brennan and Noggle’s “Equal Moral Consideration Thesis” by showing that children’s embodied experience of illness leads them to try to make sense of what they are going through; their moral status

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[98] Brennan, S., and R. Noggle, (1997) p. 1.
[99] Brennan, S. and R. Noggle, (1997). p. 2.

therefore, demands moral consideration for their information and participation needs.

Even very young children, incapable of fully rational decision-making, have the capacity to value; I will briefly show that this is yet another reason that they deserve moral consideration. I will argue that all children, given the moral status attributed to them by their personhood, are deserving of consideration as moral agents and discount arbitrary age limits that unfairly and unnecessarily restrict pediatric patients' opportunities to exercise their autonomy.

After I have established that children can possess the capacities for autonomy, I will show that my claim has been adopted into important pediatric health care guidelines by reviewing the Canadian Paediatric Society's position statement on involving children in health care decision-making. However, I will also offer an example of the ease with which children's autonomy claims can be denied, by reviewing the Supreme Court of Canada case, *A.C. v. Manitoba (Director of Child and Family Service,.)* and introduce the idea that hidden, oppressive social forces might be responsible for this trend.

The Moral Status of Children:

In their attempt to provide a philosophical foundation for the moral status of children, Brennan and Noggle first argue that children merit moral *consideration* equal to that which we accord adults. They caution that this is not to say that we owe children the same duties and rights as adults, nor that they can take on the full burden of adult responsibilities, only that children are equally worthy of moral consideration as persons.

> The basis for the Equal Consideration Thesis is the fact that children are persons. Because they are persons, they are entitled to the same moral consideration to which anyone is entitled merely in virtue of being a person. In other words, a certain moral status attaches generally to all persons, including children. To deny this would be to claim either that persons do not derive moral status from their status as persons, or that children are not persons. Because neither of these claims is particularly plausible, it does not seem plausible to deny the Equal Consideration Thesis.[100]

Next, Brennan and Noggle argue that: "children - at least at certain ages – can be legitimately prevented from doing certain things that it would be illegitimate to prevent adults from doing."[101] They refer to this as the "Unequal Treatment Thesis," and argue that its practical appeal is undeniable in general public policy. They list a host of things that we allow adults, but not children to do, such as drinking, driving, and owning firearms.

Brennan and Noggle admit that these two claims appear inconsistent, because it is hard to reconcile "unequal treatment" with the idea that children possess full and equal moral status and rights as persons. In order to reconcile these two claims, Brennan and Noggle explain that although "much of the moral status a person has comes simply from the fact that she is a person…A person's moral rights and duties typically depend on many other things in addition to her status as a person. Roles, for example, often confer moral status."[102]

Accordingly, they argue that children's immaturity and lack of life experience precludes them from fulfilling certain important roles, and if children

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[100] Brennan, S. and R. Noggle. (1997). p. 3.
[101] Brennan, S. and R. Noggle. (1997). p. 3.
[102] Brennan, S., and R. Noggle,, (1997). p. 6.

cannot fulfill the role in question, then it is reasonable to deny them the role-dependent right; this explains how children can justifiably be treated differently from adults in important regards. The crux of their argument is that,

> The reason that unequal treatment is consistent with equal consideration lies in an important difference between two kinds of rights. On the one hand, there are basic rights (often called "human rights") that everyone has; they attach to persons simply in virtue of their being persons. The rights not to be harmed or killed fall into this category. On the other hand, some rights are constructed from basic moral rights plus other factors. They depend in part on facts about the persons who bear them, facts about the relationships of which they are a part, facts about previous commitments they have made, and facts about the societies in which they live. Often these constructed rights are attached to roles... Thus the relative lack of maturity of children counts against their having certain role-dependent rights; since they are not mature enough to play those roles, they cannot have the rights attached to them. [103]

Brennan and Noggle explain that in order to have the rights and duties related to a role,

> It requires certain qualifications consisting of skill, judgment, training, and so on. Because children lack these qualifications, they can be legitimately denied the rights associated with [the] role. We do not deny this right to children simply because they are children, but because they lack the relevant abilities.[104]

However, even though Brennan and Noggle are seeking to justify their "unequal treatment thesis" in relation to children, they admit that,

> To accord someone equal moral consideration is to do two things. First, it is to respect the moral status she has merely in virtue of being a person. Second, it is to be willing to consider any other moral claims she might make due to other factors that affect her moral status. So whether unequal treatment is consistent with equal moral consideration will depend on the nature of the differential treatment at issue. That is, equal moral consideration is compatible with some sorts of inequalities in treatment but not others.[105]

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[103] Brennan, S., and R. Noggle, (1997). p. 7.
[104] Brennan, S., and R. Noggle, (1997). p. 8.
[105] Brennan, S., and R. Noggle, (1997). p. 6.

In the context of health care, the role played by the child and the adult is the same; it is the role of "patient." Although to be a patient does not require any real qualifications nor hold any duties or obligations, to be an autonomous patient does. As explained earlier, respect for autonomy is not absolute in bioethics; patients must demonstrate certain skills and their decisions must meet certain qualifications in order to merit respect as autonomous. Therefore, according to Brennan and Noggle's argument, if children merit equal moral consideration, and if they possess the necessary qualifications for autonomy, then there would be no legitimate reason to deny their autonomy, i.e. to treat them differently. In the next section, I will show that children are capable of meeting the requirements for respect for autonomy.

Autonomy, Competency, Capacity, and Canadian Health Law:

Autonomy reflects a capacity to make a rational decision according to an understanding of what is at stake and according to a coherent set of personal values and goals. To be autonomous is not simply to make choices, but to make choices with understanding, that are intentional, and without controlling influences.[106] Beauchamp and Childress explain that respect for autonomy "obligates professionals in health care…to disclose information, to probe for and ensure understanding and voluntariness, and to foster adequate decision making."[107] Accordingly, demonstration of certain capacities on the part of the patient is required before a decision should be respected as truly autonomous.

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[106] Beauchamp, T., and J.F. Childress, (2009). p.101.

[107] Beauchamp, T. and J. F. Childress, (2009). p. 104.

Current Canadian medical law requires that several criteria be met in order to accept consent to medical treatment as valid. These criteria closely mirror Beauchamp and Childress' criteria for respecting autonomous decisions. The Canadian criteria for valid informed consent require that the patient must: (i) be legally competent, (ii) have the required mental capacity to authorize care, (iii) be provided with proper information delivered in an impartial manner, (iv) have an opportunity to ask questions, and (v) that the authorization be specific to the proposed treatment and free of undue influence or coercion.[108]

The presumption that children lack both legal competence and mental capacity are two primary reasons why it has been harder to establish respect for pediatric autonomy in bioethics. I believe the association of certain legal concepts with the concept of autonomy has mistakenly helped to exclude children from the autonomy debate. However, upon review, it would seem that Canada's legal system is less prone to such exclusionary attitudes than these links would imply.

The concepts of competence and capacity are often used interchangeably in both bioethics and in law but reflect two different concerns. According to Rozovsky, author of *The Canadian Law of Consent to Treatment*, "the law presumes that all patients - including children - are legally competent to give an authorization for treatment."[109] However this presumption is not absolute, and can be denied by legislation or court order. For example, some provinces legislate an age of consent to medical treatment for children, below which a person cannot legally provide consent.

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[108] Rozovsky, L. (2003). The Canadian Law of Consent to Treatment, 3rd Edition. Markham, Ontario, Lexis Nexis Canada Inc. p. 6.

[109] Rozovsky, (2003). p. 7.

To be legally competent is to hold a particular kind of legal status, one that is attributed to persons who possess the particular abilities required to accomplish certain tasks, hence the term "competence". This status grants persons a legal right to make certain decisions in certain domains of their own lives. Therefore, one can be found to be legally competent in one regard, for example, to consent to medical treatment, but not legally competent in others, for example, in managing their financial assets. This is an important point to establish, because it speaks to Canada's recognition of the fact that different kinds of abilities are required to be competent in different areas, and affirms that it is possible for even a child to be legally competent to consent to medical treatment, while perhaps not legally competent to act autonomously in general, or in other particular areas of their lives.

Mental capacity "refers to the intellectual ability to reach a reasoned choice about treatment." [110] Given that mental capacity entails the presence of certain abilities, it is also sometimes referred to as mental "competence." In regard to Canada's health law, Rozovsky elaborates:

> A person's mental ability to consent to treatment must not be assumed from his or her status within either the health care system or the legal system. While this status may be evidence regarding the person's ability to consent, it is not definitive. A person's ability to consent to treatment depends upon the following factors:
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> 1. The ability to understand that he or she has the right to either consent to or refuse treatment; and
> 2. The ability to understand the information given to him or her and upon which the decision will be based, including the nature, risks, and benefits of treatment, and any reasonable alternatives to the proposed treatment along with the nature, risks, and benefits of those alternatives.[111]

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[110] Rozovsky, (2003). p. 7.
[111] Rozovsky, (2003). p. 64.

Hence, Rozovsky explains that, "in the absence of legislation to the contrary, if a minor is capable of discerning the nature, purpose, risks and benefits of treatment, that individual should be treated as a mature person capable of giving consent to treatment."[112]

The above passage suggests that the law does not exclude children from medical decision-making based solely on their status as minors; children who can prove their mental capacity can be legally competent to consent. In this regard, Canadian common law does not appear to reflect Brennan and Noggle's assertion that general public policies embrace their "Unequal Treatment Thesis." Of course, it remains to be shown whether pediatric patients can be capable of understanding complex health information and the risks and benefits of proposed medical treatment, to the degree required to grant them respect for their autonomy.

The Beginnings of Pediatric Autonomy:

In 1978, at roughly the same time that respect for patient autonomy was being introduced as a fundamental principle of biomedical ethics, Myra Bluebond-Langner published her book, *The Private Worlds of Dying Children*, based on field research she undertook while studying childhood socialization. Her study group consisted of children between the ages of 3 and 9 who had been diagnosed with leukemia. In 1978, childhood leukemia was much less often successfully treated and in fact, all of Bluebond-Langner's study patients were considered terminal and all eventually died.

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[112] Rozovsky, (2003). p. 9.

Of particular historical interest is the general approach that all the implicated adults - parents, doctors, nurses, and other health care providers - took in treating the children. In fact, they conspired to prevent any of the children from learning that they had leukemia, and that they were dying. Despite their attempts to "protect" the children from the diagnosis and what it implied, Bluebond-Langner discovered that the children knew considerably more about their illness than their parents or health providers realized and eventually, individually deduced that they were dying.

However, taking cues from the adults around them, they also inferred that the subject was taboo, and individually strived to behave in what they assumed was the most socially acceptable way; they did not openly admit that they were dying, or attempt to discuss it with their doctors or parents. They struggled to uphold what Bluebond-Langner termed "mutual pretense" wherein the parties all know the patient is dying but act as if she is not.[113] The children's only forum for openly discussing their illness was with each other, out of ear-shot of their accompanying adults, in the play room of the hospital's Oncology Clinic.

Bluebond-Langner's focus was anthropological, and her main goal was to study how and why even dying children would struggle to behave in socially acceptable ways; however, her study brought about a gestalt switch that helped abolish the practice of withholding health care information from children. Her work prompted a new perspective that allowed pediatric patients opportunities to participate in their health care.

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[113] Bluebond-Langner, (1978). p. 198.

The first telling aspect of her study was the discovery that the children, ranging in age from 3 to only 9 years old, were capable of inferring much about their condition from their own illness experience. They also learned important information from sharing in the experiences of other children, either through conversation with them at the clinic, or by witnessing events first hand when they were hospitalized together. For example, even children who could not name their illness understood it as a series of remissions and relapses. They learned that there were a relatively limited number of drugs that were prescribed to attempt to bring about a remission, and knew their names and side-effects. They were adept at figuring out when they would have to undergo certain tests or procedures, even when the adults in their lives didn’t tell them, and eventually, when one of the children they knew died, they inferred that the illness would eventually kill them too.

Bluebond-Langner established five stages of illness awareness that the children passed through at different speeds. Progression from one stage to the next was attributed to personal experience as well as the experiences of other children they witnessed throughout the course of their own illness. The children went from conceiving of themselves as “well,” to “seriously ill,” then “seriously ill and will get better,” “always ill and will get better,” “always ill and will never get better,” and lastly “dying.”[114]

> For two major reasons, experience was critical to passage through the stages. First, the children needed the disease experiences (e.g. nosebleeds, relapses, bone pain) to gather significant disease-related information. At any stage of illness, the children were taken to the clinic, where they could again meet their peers and

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[114] Bluebond-Langner, (1978). p. 169.

> discuss what was happening to them. Second, the disease experience enabled them to assimilate this information by relating what they saw and heard to their own experience. The children did not ask about things that were not happening to them…The role of experience in developing awareness also explains why age and intellectual ability were not related to the speed or completeness with which the children passed through the stages.[115]

Given that her study patients ranged in age from only 3 to 9 years, and that they received no information from adults at all, it is extraordinary how much accurate practical knowledge about their illnesses they were able to deduce from personal experience alone. Although Bluebond-Langner does not specifically address how the attempt to uphold "mutual pretense" was burdensome to the children, there are clear examples within the text of children feeling frightened, lonely, and distrustful of their parents and doctors because they knew they were not fully disclosing the truth.

Bluebond-Langner's findings show that children, regardless of their age, live the embodied experience of illness. This would seem to confirm that child patients, like all persons, deserve ethical treatment and consideration of their perspectives and information needs within bioethical discourse.

Furthermore, in a move away from according autonomy based solely on rationality, more recent perspectives link autonomy with agency which children may be more readily agreed to possess. In her article "Respecting the Margins of Agency: Alzheimer's Patients and the Capacity to Value," Jaworska argues that autonomy should not be awarded based on whether people can make rational decisions within a complete narrative, taking into consideration their life as a whole, but rather that anyone who has the capacity to value has some claim to

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[115] Bluebond-Langner, (1978). p. 168-9.

agency and therefore to autonomy. This confirms not only that pediatric patients should have some right to make decisions according to their own set of values, but also that the ability to value affirms children's moral status.

> The very ability to value, even if more instrumental abilities are absent, supplies the starting points for the exercise of autonomy, and thereby renders the person capable of autonomy. Of course, possessing the capacity to value does not guarantee that the person can exercise autonomy to a full degree. Full-blown autonomy involves not only acting on one's own principles and convictions, but also the ability to scrutinize these principles and to revise them in light of critical evaluation, so that they are well-articulated and robust.[116]

The traditional conceptualization of children as immature and irrational reduces children's values, beliefs and desires to mere epiphenomena, and prevents their accepted agency from translating into a measured respect for their moral status and their individual autonomy competency.

Evidence Against Arbitrary Age Restrictions:

It is reasonable to say that children who <u>cannot</u> meet the conditions required to merit respect for their autonomy, should not be allowed to independently consent or dissent to health care decisions that affect them. It is quite another to say that we have no duty to help children reach a level of autonomy competency that would allow them to do so or to accept that even children who are shown to be competent should be denied the opportunity to exercise their autonomy based solely on their age.

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[116] Jaworska, A. (1999). "Respecting the Margins of Agency: Alzheimer's Patients and the Capacity to Value," <u>Philosophy and Public Affairs</u> **28**(2): 105-138. p. 130.

The idea that age, mental competency and autonomy share a strict correlation has been disproven in several studies.[117, 118, 119, 120] These studies have demonstrated that illness experience gives children a framework from which it is easier to understand complex information about their illness and puts them in a position to reason competently about treatment decisions. This is one of the primary reasons for my argument that pediatric autonomy in health care is a particular case; since children can fulfill the requirements to be considered autonomous, their unequal treatment cannot be justified under Brennan and Noggle's "Unequal Treatment Thesis."

Priscilla Alderson *et al's* 2006 study entitled "Children's competence to Consent to Medical Treatment," showed that children who have medical decision-making experience are more capable of participating in their own health care and that age is not necessarily a limiting factor. Her study focused on the decision-making abilities of children dealing with juvenile (Type 1) diabetes and found that "children can fulfill the criteria of competent decision-making as identified in some of the landmark documents on informed consent to medical research."[121]

Her study recognized the importance of including diabetic children in their own care for their safety. Diabetic children must make health related decisions on a daily basis to simply navigate through their daily routines. They must test their blood glucose, eat appropriately, respond to daily temptations to eat things they

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[117] Alderson *et al*. (2006). "Children's Competence to Consent to Medical Treatment."

[118] Alderson, P., K. Sutcliffe, *et al*. (2006). "Children as partners with adults in their medical care." Archives of Disease in Childhood **91**: 300-303.

[119] Bluebond-Langner, (1978)

[120] Rushforth, H. (1999). "Practitioner Review: Communicating with Hospitalized Children: Review and Application of Research Pertaining to Children's Understanding of Health and Illness." Journal of Child Psychology and Psychiatry and Allied Disciplines **40**(5): 683-691.

[121] Alderson *et al.* (2006). "Children's competence to Consent to Medical Treatment." p. 25.

should not, coordinate their food intake with their level of physical activity, take appropriate doses of insulin to balance all the rest of the factors at play, and be prepared and equipped to urgently recognize and handle the situation when their blood sugar levels fall below normal.

It is enough to make an adult dizzy, yet children who have a basic understanding of their illness and its requirements for care seem to balance all of these things remarkably well. In fact, they must. A miscalculation in food intake or insulin dosage can lead to dangerously low blood sugar states which can lead to hypoglycemic coma, or high blood sugar levels which have serious long term consequences such as blindness, kidney failure and diabetic neuropathy requiring amputation.

Alderson’s study confirms that children who are afforded an opportunity to participate in their health care can develop the skills necessary for competent medical decision-making. Having experienced the condition and consequences of both high and low blood sugar levels, these children are in a position to appreciate the benefits of following their treatment plans, and the risks associated if they do not. Their understanding of their illness and its potential consequences also facilitates compliance with unpleasant obligations such as finger pricks for blood glucose testing, multiple injections of insulin every day and hospital visits.

Of course, unsurprisingly, not all of the children studied by Alderson were capable of responsibly managing their diabetes. However, what is important to note in Alderson’s study is that age was not a clearly determining factor of capability. Alderson’s evidence suggests that despite the practical benefits of assigning a set age requirement below which patient autonomy is not considered, any such limit would be simply arbitrary.

In response to an article by David Wendler and Seema Shah in which they argue that children should be allowed to make research participation decisions from the age of 14, Francoise Baylis and Jocelyn Downie argue just that; arbitrary age limits are pragmatic but insufficient. They believe that pediatric patients deserve the same kind of individualized assessment that we grant adults of questionable competency, and that Canadian law seems to promote. In "The Limits of Altruism and Arbitrary Age Limits," they assert:

> We reject Wendler and Shah's claim that "the practical difficulties involved in assessing children's understanding and appreciation of the proposed research support the use of a general age threshold rather than a requirement that investigators assess every child individually." The implications of this position are deeply problematic. By analogy one would have to conclude that because of practical difficulties in assessing the capacity of elderly persons and persons with certain mental disabilities, there should be a general upper-age threshold for the elderly (e.g., 80) and a disease-category threshold for those with certain mental disabilities (e.g., schizophrenia). In contrast, however, there is a widespread acceptance of the need for individualized capacity assessments for persons in these groups. By analogy, there should be individualized capacity assessments for minors where there is the possibility that they might be competent.[122]

Evidence has shown that relevant illness experience fosters maturity and encourages the development of certain cognitive abilities that lend themselves to autonomy. Furthermore, the feminist argument that autonomy admits of degrees, is developed through its exercise, and that autonomy competency might be more or less developed for application based on the particular context of the decision

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[122] Baylis, F. and J. Downie (2003). "The Limits of Altruism and Arbitrary Age Limits." American Journal of Bioethics **3**(4): 19-21. P. 20.

required, all support my argument that our different approach to pediatric versus adult autonomy in health care, cannot be justified by Brennan and Noggle's "Unequal Treatment Thesis."

Current Practice (at least in theory…) :

In a 2004 position statement entitled "Treatment decisions regarding infants, children and adolescents," the Canadian Paediatric Society (CPS) offers several principles to guide pediatricians in involving their patients in decision-making. These principles reflect some of the new feminist conceptions of autonomy, and uphold the kind of moral status for children that I have been arguing for. The following principles and assertions are quoted directly from the Canadian Paediatric Society's position statement:[123]

- Just as the concept of informed choice has evolved over the last 30 years, new consideration of children's role in decision-making has evolved.

- Capacity is not age- or disease- related, nor does it depend on the decision itself, but is a cognitive and emotional process of decision-making relative to the medical decision.

- Children who have partial skills to make decisions should be recognized as having some authority over their own health care.

- Some pre-adolescent children, particularly those with much experience with illness, may have enough medical experience and cognitive skills to make their own medical decisions.

- Children and adolescents should be appropriately involved in decisions affecting them. Once they have sufficient decision-making capacity, they should become the principal decision-maker for themselves.

- To deny decision-making to mature adolescents may be interpreted as a violation of their fundamental rights.

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[123] Bioethics Committee, Canadian Paediatric Society, (2004).

Furthermore, in *Canadian Medical Law*, Sneiderman *et al* confirm that the kind of evidence I presented above that speaks to the mental capacities of children with illness experience, has been accepted within Canadian medical law and reflects an important social trend in regards to our ideas about children.

> Although there is uncertainty and unpredictability on issues involving the medical treatment of minors, the general trend is apparent. Both the common law and legislation are lowering the age at which minors have the capacity to consent to medical treatment. This trend is very much in line with broad social patterns. Children mature earlier, physically, socially and intellectually and are confronted at an earlier age with significant medical problems about which they are better educated and better informed than has been true in the past.[124]

Both the Canadian Paediatric Society's position statement on the involvement of children in their own medical decision-making, and the intentions behind Canada's medical law in regards to children, as expressed by both Rozovsky and Sneiderman *et al*, are encouraging. However, despite recognition that children who are mentally capable should be respected as such in terms of medical decision-making, it appears that it is still more difficult for children to have their autonomy claims respected. What could explain this trend?

In practice, we continue to see pediatric autonomy claims ignored or undermined. For example, as recently as 2004, Carnevale addressed the moral objectification of children, the denial of their moral agency, and the trivialization of their perspective and voice in his work. It is here that the feminist criticism of the traditional concept of autonomy is perhaps most apt. Feminists argue that the

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[124] Sneiderman, B., J. Irvine, *et al*. (1995). Canadian Medical Law: An Introduction for physicians, Nurses and other Health Care Professionals, 2nd Ed. Scarborough, Ontario, Carswell Thomson Professional Publishing. p. 51.

ways in which supportive or oppressive social conditions can foster or hinder autonomy tend to be overlooked; once these social conditions are uncovered, this will explain the continued denial of pediatric autonomy claims in practice.

In the case, *A.C. v. Manitoba (Director of Child and Family Services),* the Supreme Court of Canada upheld the constitutional validity of a treatment order that imposed an unwanted blood transfusion upon an adolescent girl who was shown to be competent. Despite the court's finding that the treatment order was constitutional, this case is of particular importance for several reasons.

First, there is no absolute right to appeal to the Supreme Court of Canada. The fact that the motion to be heard in the Supreme Court was granted implies that the court recognized the magnitude and consequence of the denial of this competent adolescent's autonomy.

Second, the comments of the court reflect the same respect for the developing capacities and maturity of children that I have presented here. Although the court upheld the constitutionality of the applications judge, Kaufman J.'s decision, both the majority judges and the dissenting judge criticized Kaufman J.'s failure to respect the spirit of the law by his assumption that A.C.'s competence was irrelevant to the case due to her age and his disregard for A.C.'s input into her own best interests. The importance of the issue of pediatric autonomy is further reflected by the court's unanimous decision to award A.C. her costs in the Supreme Court and the courts below.

A.C. v. Manitoba (Director of Child and Family Services):

In 2006, A.C. was admitted to a Manitoba hospital at 14 years and 10 months of age for gastrointestinal bleeding secondary to Crohn's disease. A.C. also happened to be a devout Jehovah's Witness and had signed an advanced medical directive months earlier refusing blood transfusions under any circumstances. The doctor, fearing that the bleeding was an imminent threat to her health and possibly her life, and uneasy about her sustained treatment refusal, sought a court order to force her to accept a blood transfusion. The Manitoba Director of Child and Family Services subsequently apprehended her as a child in need of protection.

The applications judge, Kaufman J., relying upon testimony from A.C.'s treating physician, granted the treatment order. However, somewhat ironically,

> At the urging of her counsel, he agreed to proceed on the assumption that A.C. had "capacity" to make decisions because, in his view, her capacity was irrelevant to his task. Even though she did not wish to receive blood, he concluded that based on the Manitoba Family Services Act under which she was apprehended, when a child is under 16 years old, "there are no legislated restrictions of authority" on the court's ability to order medical treatment in the child's "best interests"."[125]

The court order having been obtained, A.C. was administered a total of three blood transfusions and recovered.

Later, A.C. and her parents appealed the judgment, arguing that it was unconstitutional under several sections of the Canadian Charter of Rights and Freedoms. They argued that the Manitoba Child and Family Services Act

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[125] (2009). *A.C. v. Manitoba (Director of Child and Family Services*), [12].

legislation denied A.C. a right to demonstrate her capacity based on her age; therefore, this legislation infringed upon her equality rights under the Canadian Charter of Rights and Freedoms, (children over 16 were granted that right in the Family Services legislation.) They also argued that her freedom of religion had been infringed, and that the court had no right to impose treatment in her best interests when she was competent and in no need of the court's protection.

Two aspects of the case are of particular interest. The first is that although A.C. underwent psychological evaluation by three separate psychiatrists at the hospital, all of whom found her competent to make decisions for herself, Kaufman J., did not have the reports analyzed by the court, or enter them into evidence. This is because on Kaufman J's reading of the law, his duty was to protect A.C.'s best interests, regardless of her ability to demonstrate mature medical decision-making capacity.

> Under the *Child and Family Services Act*, where either the child or the child's parents refuse to consent to recommended medical treatment, the court has the power under s. 25(8) to consider whether authorizing treatment against the wishes of the parents and/or child is in the child's best interests. Section 25(9) presumes that the best interests of a child 16 or over will be most effectively promoted by allowing the child's views to be determinative, unless it can be shown that the child lacks the maturity to understand the decision or appreciate its consequences. Where the child is under 16, no such presumption exists. [126]

Based on this, it was found that the decision of the applications judge to order treatment conformed to the provisions of the Act, and therefore, his decision was upheld by both the Court of Appeal for Manitoba and the Supreme Court of Canada.

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[126] (2009). *A.C. v. Manitoba (Director of Child and Family Services)*, [24].

The second aspect is the regrettable failure of Kaufman J. to consult A.C. in regard to her own best interests because she was under the age of 16. In fact, Kaufman J. refused to speak to A.C. or to facilitate her participation in the hearing. The best interests standard set out in section 2(1) of the Child and Family Services Act requires that: "the child's mental, emotional, and physical stage of development," as well as, "the views and preferences of the child where they can reasonably be ascertained" and "the child's cultural, linguistic, racial and religious heritage"[127] all be considered; however, upon a literal interpretation of section 25(9) of the Act, quoted above, Kaufman failed to consult A.C.

Justices LeBel, Deschamps, Abella and Charron assert that the constitutionality of the law can only be upheld when the law is applied in the spirit in which it is intended.

> When the young person's best interests are interpreted in a way that sufficiently respects his or her capacity for mature, independent judgment in a particular medical decision-making context, the constitutionality of the legislation is preserved. Properly construed to take an adolescent's maturity into account, the statutory scheme strikes a constitutional balance between what the law has consistently seen as an individual's fundamental right to autonomous decision making in connection with his or her body, and the law's equally persistent attempts to protect vulnerable children from harm. The "best interests" standard in s. 25(8) operates as a sliding scale of scrutiny, with the child's views becoming increasingly determinative depending on his or her maturity.[128]

Kaufman J.'s unfortunate interpretation of the best interests standard may have left this young woman, a devout Jehovah's Witness, in the rather undesirable position of believing that the court ordered blood transfusion has cost her eternal

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[127] Section 2(1)(c)(f) & (h) of the Child and Family Services Act as quoted from: (2009). *A.C. v. Manitoba (Director of Child and Family Services)*, [32].

[128] (2009). *A.C. v. Manitoba (Director of Child and Family Services)*, p. 3.

life, and possibly the continued support of her religious community. Kaufman's narrow perspective on the best interests standard did not escape criticism. According to Justice Abella J. (LeBel, Deschamps, and Charron concurring), the best interests standard,

> Does not mean, as Kaufman J. in this case seemed to suggest, that the standard is a licence for the indiscriminate application of judicial discretion. To divorce the application of the best interests standard from an assessment of the mature child's interest in advancing his or her own autonomous claims would be to endorse a narrow, static and profoundly unrealistic image of the child and of adolescence.[129]

The sole dissenting Supreme Court judge Binnie J., went even further in his criticism, declaring that "forced medical procedures must be one of the most egregious violations of a person's physical and psychological integrity against the will of an individual whose refusal is based on a strong religious faith."[130] Furthermore, Binnie J. agreed with A.C. that "the state's interest in ensuring judicial control over the medical treatment of "immature" minors ceases to exist where a "mature" minor under 16 *demonstrates* the lack of need for any such overriding state control."[131]

This leaves us with the question of why, despite clear evidence and support for accepting the autonomy competency of children, especially adolescents, when push comes to shove, respect for pediatric autonomy is often sacrificed in favour of other interests. After a review of relevant Canadian and international jurisprudence, Justices Abella, LeBel, Deschamps, and Charron, explain that:

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[129] (2009). *A.C. v. Manitoba (Director of Child and Family Services)*, [91].
[130] (2009). *A.C. v. Manitoba (Director of Child and Family Services)*, [167].
[131] (2009). *A.C. v. Manitoba (Director of Child and Family Services)*, p. 6.

> What is clear from the…survey of Canadian and international jurisprudence is that while courts have readily embraced the concept of granting adolescents a degree of autonomy that is reflective of their evolving maturity, they have generally not seen the "mature minor" doctrine as dictating guaranteed outcomes, particularly where the consequences for the young person are catastrophic.[132]

Despite the importance of this case in establishing the legal system's respect for pediatric capacities, disturbingly, the section of the Manitoba Child and Family Services Act that outlines the best interests standard, and which was fundamental to this case, was amended by the province of Manitoba following the hearing in the Supreme Court.

Originally section 2(1) of the Child and Family Services Act read, **"**The best interests of the child shall be the paramount consideration of the…court in all proceedings under this Act affecting a child…and in determining the best interests of the child all relevant matters shall be considered, including…"[133] Following the Supreme Court hearing, the Act was amended and now states, "The best interests of the child shall be the paramount consideration of the…court in all proceedings under this Act affecting a child…and in determining best interests <u>the child's safety and security shall be the primary consideration. After that</u>, all other relevant matters shall be considered, including…"[134] The purpose of this amendment is obvious. The difference in the wording serves only to uphold the Court's legal right to impose its own conception of the patient's best interests upon even competent adolescents.

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[132] (2009). *A.C. v. Manitoba (Director of Child and Family Services)*, [69].

[133] (2009). *A.C. v. Manitoba (Director of Child and Family Services)*, Appendix: Section 2(1), p. 66.

[134] (2009*). A.C. v. Manitoba (Director of Child and Family Services),* Appendix [1] p. 67. (my emphasis added.)

In the particular case of *A.C. v. Manitoba (Director of Child and Family Services)* it is hard to fathom what justification could be offered for the denial of A.C.'s autonomy claim. Beauchamp and Childress explain that,

> To respect autonomous agents is to acknowledge their right to hold views, to make choices, and to take actions based on their personal values and beliefs. Such respect involves respectful *action*, not merely a respectful *attitude*…Respect, in this account, involves acknowledging the value and decision-making rights of persons and enabling them to act autonomously, whereas disrespect for autonomy involves attitudes and actions that ignore, insult, demean, or are inattentive to others' rights of autonomous action.[135]

A.C. was able to explain to the three psychiatrists charged with determining her competency an appropriate understanding of her illness, the suggested treatment, alternatives to that treatment, and the potential consequences of refusing treatment, including her possible death. A.C. was also able to explain her reasoning, stating that she was refusing treatment "based on scripture "to maintain a clean standing with God,""[136] but denied feeling coerced by her parents. Her parents supported her decision and affirmed that this decision was in keeping with her relationship with God.

The psychiatric assessment report concluded:

> The patient appears to understand the nature of her Crohn's illness (and GI bleeding) and reason for admission. She also appears to understand the nature of her treatments, and that should her current medical status worsen, the treating MD's may suggest a blood transfusion. The patient understands the reason why a transfusion may be recommended, and the consequences of refusing to have a transfusion. At the time of our assessment, patient demonstrated a normal [mental status examination with] intact cognition (30/30 [Mini-Mental State Examination]).[137]

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[135] Beauchamp, T. and J. F. Childress (2009). p. 103.
[136] (2009). *A.C. v. Manitoba (Director of Child and Family Services)*, [181].
[137] (2009). *A.C. v. Manitoba (Director of Child and Family Services)*, [181-2].

In the case of A.C., I cannot think of any justifiable reason to have denied her autonomy claim, despite the potentially tragic outcome her decision may have brought about. She clearly understood her health issues, the proposed treatment, and the possible consequences of her refusal; she was choosing intentionally and without coercion. However, Justices Abella, LeBel, Deschamps, and Charron admit that there may be a tendency to deny children's autonomy claims when the consequences would be "catastrophic." Their explanation above that being declared a "mature minor" does not "guarantee outcomes," really implies that being declared a "mature minor" does not guarantee respect for autonomy.

If Canadian law is to uphold children's rights to assume greater decision-making responsibility as they mature, it will need to apply the law fairly and consistently, or risk making a mockery of legal support for children's autonomy and legal assessments of children's competency claims for health care decision-making.

> Paternalism is contrary to the ethical underpinnings of the principle of respect for autonomy. The courts now place great emphasis on the concept of autonomy and have de-emphasized the concept of paternalistic beneficence with regard to adults who have the capacity to make their own decision…The law should consistently respect patient autonomy whenever it is achievable, irrespective of age, confining the principle of paternalistic beneficence to those cases where the fundamental requirements for autonomy are lacking. This would provide consistency within the law and offer increased rigour given the empirical evidence of children's abilities.[138]

One final point to note at this juncture is the significance of Kaufman J's refusal to allow A.C. to lead evidence to support her competency or to facilitate

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[138] Haggar, L. (2009). The Child as Vulnerable Patient: Protection and Empowerment. Farnham, England, Ashgate. p. 46.

her participation in the court proceedings.[139] This is a clear example of the prevalent tendency in health care contexts to silence the voice of the child that I plan to explore in Chapter 4. Unfortunately, children's silence is usually unremarkable, explained or legitimized by accepted social norms and practices. The silencing of A.C. is particularly noticeable here, because it was so barefaced and deliberate; social forces that act to silence children are usually much more subtle.

The Veiled Role of Oppressive Social Structures:

More difficult than proving that children have capacities and values that deserve respect might be recognizing that, "efforts to protect children from having to decide about healthcare research and treatment may protect adult power as much as children's interests."[140] Despite the responsive shift in clinical practice that has been brought about by the realization that children are moral agents in their own right, there has been strong resistance to allowing them to assume full control, even when it is shown that a particular child could.

There may also exist an even more prohibitive problem to the assessment of individual pediatric capacities, which was eloquently expressed by Alderson in the concluding remarks of her study on children's competence to consent. She states that the need to revise our estimation of children's capacities,

> Involves both intellectual work and the harder ethical and emotional task of rethinking deeply held ideologies, such as the belief that adults are always right and must retain all control, or that even when older children can make informed decisions, parents should decide for them in the interests of preventing discord and sustaining harmony within the "intimate family."[141]

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[139] (2009). *A.C. v. Manitoba (Director of Child and Family Services)*, [185-6].

[140] Alderson, P. (2007). "Competent children? Minors' consent to health care treatment and research." Social Science & Medicine **65**: 2272-2283. p. 2277.

[141] Alderson *et al.* (2006). "Children's Competence to Consent to Medical Treatment," p. 32.

Conclusion:

Respect for autonomy is a relatively new principle of bioethics and one that has been borne of a particular history and shaped according to social pressures, evolving ideas about morality, and changing needs. Organized social movements helped spur the development of a more secular and responsive bioethics, and fought for more inclusive applications of the concept of autonomy. In theory, there has been a significant evolution in the value of respect for pediatric autonomy, thanks in part to the fact that relevant literature supports my claim that pediatric patients are capable and worthy of inclusion in health care decision-making and the acceptance of children's moral status. However, gaps remain in practice.

Alderson is one of very few authors who have alluded to oppressive social forces to explain this trend. Given the ideological acceptance of pediatric autonomy competency, oppressive social forces may be the last obstacle to hurdle before pediatric autonomy competencies can be fully acknowledged; a feminist bioethical analysis could be instrumental in recognizing and overcoming these oppressive social roles and structures.

In the preceding chapters, I have shown that our conceptions of children and childhood have evolved. Accordingly, we now recognize children's moral status and certain accompanying duties and responsibilities towards children that were previously undervalued. Since a relational approach to autonomy can better address oppressive social forces, the next chapter will seek to apply a relational approach to pediatric autonomy in order to investigate the role and function of oppressive social forces that impede pediatric autonomy.

Chapter 4: Social Constraints on the Development and Exercise of Pediatric Autonomy

Introduction: The New Sociology of Childhood:

In the last chapter, I argued that new ideas about children's competencies and abilities in the context of health care led to a more inclusive approach that theoretically allows children to participate more meaningfully in their own care. Over the past several decades, investigation into children's capacities for understanding complex information and their decision-making skills has been founded upon what sociologists refer to as the "new sociology of childhood;" a perspective that has broad implications for how children are perceived and treated in society at large. This new perspective stems in part from the rise of social constructivist theories that argue that social objects such as: race, gender, class and even "childhood," are social constructions rather than biological givens or obvious social facts.[142]

> The new sociology of childhood tells us that the concept of childhood should be treated as a social construction that reflects the historical, culture, values and the power structure of the particular society in which it occurs. It explains how in today's society both the concept of childhood and the image of the child have been formulated by 'developmentalists' and 'structuralists', whose insistence on treating children as passive objects or as 'human becomings' rather than 'human beings' has blinded society to children's true abilities and deafened it to their authentic voices.[143]

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[142] Corsaro, W. A. (2005). The Sociology of Childhood. U.S.A, Sage Publications Inc., p. 6.
[143] King, (2007). p. 201.

The new sociology of childhood has led to a view of children as competent, autonomous, and meaningful in their own particular state of being, i.e., deserving of respect for their unique perspectives and contributions to society; setting itself apart from the historical image of children as inherently incompetent, vulnerable, and passive "adults in waiting."[144]

Along with this change in perspective has come the recognition that children have certain rights. In "A Review of Children's Rights Literature since the Adoption of the United Nations Convention on the Rights of the Child," authors Reynaert *et al* explain that,

> Our literature review shows a preoccupation in the scholarly work on children's rights with a changing image of childhood that considers children as autonomous beings. The image of the autonomous child is considered as an evolution to a more human dealing with children in both practice and policy. It is without doubt to the merit of the children's rights movement that it has grasped the concept of individualization and brought to the fore a group in society that has for a long time been invisible and discriminated against on the basis of age.[145]

According to Helen Rushforth, the landmark *United Nations Convention on the Rights of the Child* document, "advocated amongst its key principles that children had a right to be heard regarding any decision affecting their life, and to have their views taken into account in the decision-making process."[146]

> Pertinent examples include enhanced choice for children in cases of separation and divorce, and a greater say in decisions pertaining to their medical treatment and care delivery. Underpinning such an approach is the principle within the 1989 Children Act which acknowledges not parental rights but rather children's rights and parental responsibility. However…such moves are currently in their infancy, and the acceptance by society of children's rights in a variety of domains still has some way to go.[147]

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[144] Reynaert *et al*. (2009). p.520.

[145] Reynaert *et al.* (2009). p. 522.

[146] Rushforth, H. (1999). p. 686.

[147] Rushforth, (1999). p. 686.

The prevalence of this new perspective that legitimizes children as autonomous agents, seems to underlie the recent focus on child rights, the idea that children can participate in their own health care decisions, and even current Canadian common law. However, as Rushforth points out above, and as I have argued in particular relation to health care, gaps in practice remain. Since there is what appears to be a clear *theoretical* acceptance of children's potential for autonomy in both health care, law, and society at large, and since there is evidence that children can meet the requirements for competence, overcoming unacknowledged social forces may be the last hurdle that pediatric patients face in terms of developing and being allowed to exercise their autonomy.

How Social Forces can Impede Pediatric Autonomy:

MacKenzie and Stoljar identified three main levels at which autonomy can be affected by social forces. The first level is that at which an individual forms their own desires, beliefs and attitudes, including beliefs and attitudes they adopt about themselves. The second level pertains to the development of the skills necessary to become autonomous, including those necessary for self-reflection, and the third level pertains to an individual's ability to make autonomous choices or to act autonomously, which can be directly affected by social norms, practices, institutions or relationships.[148] These levels are of course, highly interrelated.

It would be beyond the scope of this thesis to identify all of the social forces that potentially affect pediatric autonomy and analyze their effects. Therefore, in the next three sections, I will use one example to illustrate how

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[148] Mackenzie, C., & N. Stoljar (2000). p. 22.

social forces affect children on each of the three levels, and illustrate how those forces frustrate their ability to develop or exercise autonomy in health care contexts.

In Chapter 2, I reviewed Susan Sherwin's argument that how information is relayed to patients so that they can make informed, autonomous decisions can be problematic. Sherwin focused on the relatively higher socio-economic status of physicians versus the majority of their patients, and explained how this gap in status can affect how information is shared and understood. Information and understanding are crucial to autonomous decision-making and determinations of autonomy require communication skills; therefore, I have chosen to explore how social forces can negatively affect communication between adults and children on all three levels identified by MacKenzie and Stoljar, in such a way as to affect the development, recognition and exercise of autonomy in pediatric patients.

Studies that address the impact of social forces on pediatric autonomy are rare; however, some authors are starting to recognize that there is a link.[149] In order to reinforce my claim that social forces can affect a child's ability to communicate effectively with adults, especially with physicians or health care providers, in the next three sections I will extrapolate supporting evidence from several small studies and examine two feminist authors writing on the topic of self-trust and autonomy. The collection of findings taken from these sources reveals that social forces act to silence the voice of the child. This silencing of the

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[149] i.e. Priscilla Alderson is the most prolific writer I have found who addresses this topic specifically to some degree in most of her articles.

pediatric voice then severely limits the child's ability to develop the skills necessary for autonomy and limits their opportunities to exercise their autonomy.

How Social Forces Affect Child-Physician Communication and Inform the Development of Children's Beliefs and Attitudes, Including Beliefs and Attitudes they Adopt About Themselves:

As discussed in Chapter 3, Myra Bluebond-Langner's field work with dying children revealed that although the children knew they were dying, they did not try to discuss this fact with their parents or physicians. Bluebond-Langner deduced that the children remained silent in this regard because they had inferred from the social cues that the adults were sending that death and dying are taboo subjects, not to be discussed. Instead, the children struggled to uphold what Bluebond-Langner termed "mutual pretense," wherein all parties know the patient is dying, but act as if she is not.

Bluebond-Langner's findings provide convincing evidence that children are sensitive to social norms and practices, and that these social forces inform the development of certain beliefs or attitudes. Here, the children's belief that death and dying were taboo subjects, prevented them from sharing the fact that they knew they were dying; therefore, they faced their ensuing fears alone. I believe this speaks strongly to the power of social norms, and children's desire to respect them.

In a more recent study, Hsiao *et al* tried to identify features that children and their parents found to be either helpful or detrimental to communication with physicians in the context of pediatric palliative care. This study suggests that the ways in which physicians communicate with children are governed by dogmatic social norms; clear messages are sent to children that physicians prefer to communicate with their parents. This in turn leads children to internalize the message that they are not good communicators, and will not be taken seriously. Once internalized, this belief can severely hinder their desire and ability to communicate their perspectives and to voice their preferences; therefore, they are robbed of the opportunity to develop autonomy skills, and to act autonomously.

Hsaio *et al* first interviewed children who were facing life threatening illness and their parents separately, and identified subthemes in their narratives which when analyzed, fit into 6 general communication domains.

> Five domains of physician communication emerged that both child and parent participants identified as salient and influencing comfort level. These included relationship building, demonstration of effort and competence, information exchange, availability, and appropriate level of child and parent involvement. Parents alone identified the sixth category, coordination of care…The primary domain of child/parent disagreement was in the level of involvement in direct communication between the child and physician."[150]

Hsiao *et al* also identified obstacles that frustrate direct child to physician communication. These included: children perceiving their parents as more knowledgeable or as better communicators; children believing that the doctor would not take information or questions directly from them as seriously as if it came from their parents; a felt need to hide concerns or emotions so as not to upset their parents; fear of receiving "bad news" and lastly, underdeveloped cognitive or verbal skills.[151]

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[150] Hsiao, J., E. Evan, *et al*. (2007). "Parent and child perspectives on physician communication in pediatric palliative care." Palliative and Supportive Care **5**: 355-365: p. 358.

[151] Hsaio *et al.* (2007) "Table 4. Obstacles to children directly communicating information to physicians," p. 362.

Comments made by some of the children in the context of the interviews seem to reflect certain beliefs and attitudes about their own abilities and communication skills that hindered their desire and ability to communicate directly with their physicians. For example; one child stated, "I guess like they [the physicians] overwhelm me sometimes and I feel easier having my mom tell them…She's a better communicator I think."[152]

The children also "emphasized the importance of doctors believing the children's words, reporting that they could tell when the physicians did not believe what the child was saying."[153] This is further supported by the fact that Hsiao *et al* identified as one obstacle to direct communication with physicians, the belief that physicians tended to take parents' comments, concerns and questions more seriously than the children's. One child stated: "That's why I always have my dad around. He's the only one that I could get them [the physicians] to listen to."[154] This child has learned from experience that it is more effective to delegate the responsibility of communicating to her father, because she feels she is being dismissed.

Another child seemed to imply that the physician was failing to fully recognize her point of view and stated: "The doctors keep on wanting to go against you instead of trying to find other ways to make it better for you."[155] Either this child is lacking some critical information about treatment that makes her feel the doctor is "going against her" or the child is trying to express her

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[152] Hsaio *et al.* (2007). p. 361.
[153] Hsaio *et al.* (2007). p. 358.
[154] Hsaio *et al.* (2007). p. 361.
[155] Hsaio *et al.* (2007). p. 360.

preferences and autonomy, but is being dismissed by the physician. Either situation is regrettable.

Although several of the children identified "bad attitude" on the part of the physicians as unhelpful to communication, none of the children identified "physician talks as though child not in room" as unhelpful, and only 15% of the parents did. One possible explanation for this fact could be that the children are informed by social norms that tend to reinforce the idea that adults prefer to speak to adults; therefore, children may not recognize this tendency as disrespectful, dismissive, or unhelpful in the particular context of the doctor-patient relationship. Instead, speaking as though the child is not in the room may appear quite normal and even socially appropriate. One child however, did seem to recognize that the onus should be on the physicians to attempt to communicate with the children rather than the other way around. She stated, "I think they [the physicians] should like approach the children instead of the children trying to approach the grown-ups."[156]

The insightful comments made by the children interviewed as part of Hsaio *et al's* study seem to illustrate that social forces present significant obstacles to a child's ability to communicate. These social forces may in fact play as important a role in silencing the voice of the child as, "underdeveloped language skills" or "immaturity." In *Between Stillness and Story: Lessons of Children's Illness Narratives*, DasGupta explains why it is not easy for children to communicate their true questions or concerns effectively to physicians.

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[156] Hsaio *et al.* (2007) p. 361.

> Much of the pediatric story emerges from nonverbal communication on the part of the child. Very young children are developmentally unable to access and to use language in the same manner as adults, but even older children are often unable to articulate their experiences, because of their social voicelessness. Despite efforts on the parts of pediatricians to elicit and to hear the voices of their patients, stronger still are the nonverbal messages transmitted to children through their parents' expectations of docility and obedience as integral to good public behaviour, adults' often obvious preference to speak directly to one another, and the very situation of being small, ill, and disrobed in a room with a stranger to whom one's parent has inexplicably conferred the power to gaze on, to probe, and to invade one's body.[157]

Hsiao *et al's* work illustrates how certain established social norms and practices that govern communication between adults and children, can inform children's beliefs and attitudes, especially those about themselves regarding their ability to communicate effectively with physicians. Communication takes place within a particular social context and it is clear that that context can discourage children from communicating effectively.

The kind of investigation undertaken by Hsaio *et al* confirms that simply inviting a child to ask questions or to express an opinion, may not be sufficient. It is clear that without a supportive social environment in which to foster effective communication skills, children's understandings, perspectives, values and goals in relation to their care plan, are unlikely to be uncovered. Therefore, the capacity to evaluate their mental competency, or recognize and respect their autonomy will be poor. The question remains, what particular autonomy skills would be necessary to facilitate effective communication with the health care team, and can they be fostered?

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[157] DasGupta, S. (2007). "Between Stillness and Story: Lessons of Children's Illness Narratives." Pediatrics 119(6): e1384-e1391. p. e1386.

In her book, *Self, Society, and Personal Choice*, feminist philosopher Diana Meyers argues that autonomous people must possess certain skills or competencies, those of "self-discovery," "self-definition," and "self-direction." The exercise of these skills leads to the development of an authentic *self* that is then capable of reflective self-governance.

> Indispensable to autonomy is the exercise of a competency which comprises an ingrained disposition to consult the self, a capacity to discern the import of felt self-referential responses as well as independent beliefs, values, and goals, and a capacity to devise and carry out conduct congruent with the self. Skillful exercise of autonomy competency not only enables people to correct perceived faults, but it also enables them to arrange their lives so as to give fuller expression to accepted qualities. In sum, it makes it possible for people to develop a sure sense of their own identities and to act accordingly – that is, to be self-governing.[158]

Meyers specifically mentions skills such as introspection, reflection and resolve throughout her chapter on autonomy competency which might mistakenly give the impression that unless one is constantly engaged in conscious self-reflection and introspection, one will never develop autonomy. However, consistent with the feminist conception of autonomy, Meyers argues that autonomy is developed through the exercise of these skills.

In fact, to some degree, each small decision we make offers an opportunity for self-reflection: to learn from consequences, reprioritize our values and goals if necessary and to adjust our practices accordingly. Therefore, Meyers' focus on self-reflection and introspection does not undermine the fact that children can develop these autonomy competencies if they have ample opportunities to exercise them.

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[158] Meyers, D. (1989). p. 84.

Although Meyers does not specifically list "self-trust" as necessary to autonomy competency, other feminist authors such as Trudy Govier, and more recently Carolyn McLeod, have argued that self-trust is a necessary attitude, vital to autonomy. In fact, the children in Hsaio *et al's* study seemed to demonstrate a lack of self-trust in their own abilities to communicate. Since the second level upon which social forces can affect a person's ability to act autonomously pertains to the development of the skills necessary to become autonomous, in the next section, I will illustrate how the social forces that discourage communication also discourage the development of self-trust and therefore, impede the development and exercise of autonomy in children.

Development of Autonomy Skills: The Importance of Self-Trust:

In her article "Self-Trust, Autonomy, and Self-Esteem," Trudy Govier argues that in order to act autonomously, one must have a sense that their values, beliefs and goals deserve consideration. One must believe that she possesses the necessary competency to make a good decision in keeping with her own legitimate values and priorities.

> To preserve a sense of who one is, to preserve the conviction that one is worthy and competent, to hold to a sense that one is leading one's life, to preserve a meaning of one's existence…against ad hoc reconstructions offered by others, to exercise autonomy and maintain self-respect and self-esteem, to function as a cognitive and moral agent, one needs self-trust…One must confidently depend on oneself to think accurately, deliberate reasonably, make sound decisions, carry out sensible plans and implement worthy goals. Without core self-trust, a person is so open to the manipulations of others as to lose any sense of a meaningful agency.[159]

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[159] Govier, T. (1993). "Self-Trust, Autonomy, and Self-Esteem." Hypatia **8**(1): 99-120. p. 115

Despite Govier's focus on the individual's sense of self, this is not to say that self-trust is developed only through internal reflection. Govier's account of self trust is very relational in that she recognizes that,

> The person who trusts himself or herself is situated in a particular context, stands in relation to other people and has beliefs, attitudes, sentiments, emotions, and memories that bear upon real people in real situations. He or she is embodied, located within a real social situation – although perhaps not fully endorsing all of its implied roles and expectations.[160]

In fact, Govier explains that development of *self*-trust is fundamentally reliant upon our social interactions with others because those interactions affect how we come to see ourselves.

> To reflect on and define one's own emotions, capabilities, motivations, and plans, one will often work with others. Interaction and dialogue have a major role to play. To insist on self-respect, self-esteem, autonomy, and self-trust is not to deny the importance of relationships with other people; nor is it to deny some proper role for these relationships in our attitudes toward ourselves.[161]

Therefore, self-trust also offers a good example of the inter-relatedness of the three levels. Govier's relational explanation of how one develops self-trust, and her assertion that self-trust is necessary in order to develop and exercise autonomy, also illustrates how social forces can affect pediatric autonomy on the level at which an individual forms their own desires, beliefs and attitudes, including beliefs and attitudes they adopt about themselves. Govier explains that,

> One may be treated as a person whose needs are of no importance, or as incompetent…or one may frequently experience frustration and failure. Such denigration or disappointment can be internalized so that a person is left with no faith or confidence in himself or herself…To put the matter simply, without self-trust a person cannot think and decide for himself or herself and therefore cannot function as an autonomous human being.[162]

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[160] Govier, (1993). p. 115.
[161] Govier, (1993). p. 116.
[162] Govier, (1993). p. 112.

In, *Self-Trust and Reproductive Autonomy*, Carolyn McLeod sets out to examine the idea that self-trust can be undermined by health care professionals and systems in ways that threaten autonomy. She explains that her work is an important contribution because,

> Neither in reproductive ethics nor in bioethics more generally has there been discussion of the value of self-trust for autonomous decision making. Those who have written about trust in bioethics...refer only to the value of being able to trust our health care providers, given how vulnerable we tend to be as patients. However, in situations of vulnerability it is important not only that we can trust others, but also that we can trust ourselves to stand up for our own interests and for what we value most. Otherwise, we relinquish our autonomy. Thus, having trustworthy professionals is not a solution on its own to patient vulnerability. An important additional element is respect for patient self trust.[163]

McLeod first questions whether *self-trust* is an appropriate topic for discussion, given that *trust* itself tends to be conceived of on inter-personal terms. She defends the use of prototype theory to extend the concept of trust in others, to trust in *oneself*. She explains that the salient features of trust within relationships, "characteristically involves certain kinds of dependency that are indicative of trust;"[164] she lists: the competence of the other in certain domains; an expectation of some similarity between what we and the trusted person stand for, morally speaking; optimism about the trusted one's commitment to act with proper motivation, i.e. with moral integrity and the trusted one's comparable perception of the nature of the interpersonal relationship. [165]

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[163] McLeod, C. (2002). Self-Trust and Reproductive Autonomy. Cambridge, Massachusetts, The M.I.T Press. p. 1.

[164] McLeod, C. (2002). p. 16.

[165] McLeod, C. (2002). p. 15-34.

While trust denotes an attitude of optimism about these features, *distrust* implies pessimism about someone's competence and moral integrity in the relevant domain. With this in mind, "we come to a rather complex understanding of what trust is prototypically. Aside from interpersonal relationality, trust [also] has prototypical features that include optimism about the trusted person's competence and moral integrity in certain domains."[166] Accordingly, McLeod goes on to argue that "self-trust is an attitude of optimism about our own competence and moral integrity, whereas self-distrust is an attitude of pessimism in that regard."[167]

Despite lacking the interpersonal, relational aspect of existing between two persons, McLeod, like Govier above, agrees that, "self-trust and distrust are relational in being socially constituted. They are molded to a significant degree by the responses of others and by societal norms."[168] McLeod demonstrates how receiving reliable social feedback, informs the development of *appropriate* self trust; without such feedback, we cannot adjust our attitudes to arrive at a *justified* level of self-trust. However, oppressive social forces can make the feedback upon which we rely, itself untrustworthy;[169] McLeod explains that patients can internalize oppressive and objectifying stereotypes and that as these attitudes become embodied in the subject, they breed self-distrust.[170]

> Oppression can interfere with a patient's trust in her ability to make autonomous choices. She might have the ability, yet be convinced otherwise because she has internalized...

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[166] McLeod, C. (2002). p. 33.
[167] McLeod, C. (2002). p. 6.
[168] McLeod, C. (2002). p. 37.
[169] McLeod, C. (2002). p. 103-131.
[170] McLeod, C. (2002). p. 70.

> [unsupportive] messages...Alternatively, her oppression...may have starved her of necessary skills for choosing autonomously, which is why she distrusts herself in that regard...The tendency to defer to the judgment of others would be natural for her; but rather than reinforce it, the physician should...take the time to guide her through the decision-making process. By allowing the patient to defer to the physician's judgment, the physician would be perpetuating her self-distrust.[171]

McLeod points out that both too much and too little self-trust will have a negative effect on autonomy and so it is important to get the balance right; consequently, she claims that "when patients are unjustified in trusting or distrusting themselves, health care providers should try to lower or bolster their self-trust respectively, in an effort to promote their autonomy."[172]

Since I have argued that children are an oppressed group in this regard and provided evidence that they are afforded relatively few opportunities to express themselves in the health care context, it is likely that they will suffer primarily from internalizing dismissive social cues that do not reinforce their competency and lead to too little self-trust. McLeod argues that,

> Autonomous agents require a supportive social environment not only to acquire autonomy skills, but to exercise the specific skills that lead to self-knowledge and justified self-trust. An environment is maximally supportive if the social forces that influence people's choices allow them to have accurate beliefs about themselves. Minimally, those forces must be nonoppressive... Oppressive social forces can inhibit self-trust at various levels of autonomous decision making. They can interfere by confusing patients about whether they are truly competent and whether they can rely on themselves to be committed to choosing and acting autonomously. In other words, oppression can prevent patients from knowing themselves, or at least from assuming that they know themselves well enough to be able to trust themselves.[173]

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[171] McLeod, C. (2002). p. 149

[172] McLeod, C. (2002). p. 89.

[173] McLeod, C. (2002). p. 130-131.

In keeping with Diana Meyers, who argued that autonomy skills such as, resolve, self-reflection and introspection, can be fostered and developed, McLeod insists that,

> Part of the task of providing encouragement is for physicians themselves to trust patients to make decisions that are right for themselves. We can hardly expect patients to trust their competency in being autonomous if physicians distrust it. Hence, it is reasonable to suppose that physicians have an obligation to trust, or at least to cultivate trust, in patients' autonomy skills.[174]

Above, I illustrated how children are sensitive to social practices and can internalize social messages in regards to their competencies. McLeod's argument, although geared towards adult patients, pertains equally well to oppressive social forces that can also affect children's abilities to develop self-trust.

Children rarely get the opportunity to make decisions; they are afforded little opportunity to express themselves, their perspectives are seldom elicited and their values are even less often honoured. On all of these levels therefore, children have little opportunity to benefit from the reliable social feedback that McLeod argues is necessary for the development of justified self-trust and self-knowledge. Instead, children receive untrustworthy social feedback, tainted by oppressive social norms, that is likely to cause the kind of self-distrust that McLeod asserts can hinder autonomy.

Likewise, it seems probable that children might also lack appropriate feedback in terms of verifying and ensuring that their understandings of their health and care are correct. This idea will be discussed in an upcoming section of fostering autonomy using work by Helen Rushforth. However, before

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[174] McLeod, C. (2002). p. 147.

undertaking a discussion of how autonomy and its required skills can be fostered in children, I want to conclude my examination of how social forces can oppress autonomy.

Next I will examine the third and final level upon which social forces can affect pediatric autonomy by investigating how the status of “family” as a social institution, can impact a child’s ability to make an autonomous decision or to act autonomously.

The Family as Social Institution: Family Centered Care:

On the third and final level, MacKenzie and Stoljar explain that the development of autonomy skills and the right to exercise them can be directly affected by social norms, practices, institutions or relationships that can impede an individual’s ability to make autonomous choices or to act autonomously.

The particular status that “family” holds as a social institution grants families the authority to organize themselves as they see fit. For example, families can assign roles to each of their members that are generally unquestioned by outsiders, and organize their own structure and relationships of power. However, the social importance of families, and the role parents play in their children’s health care, can serve to silence the children’s voices and therefore, can impact upon the development and exercise of their autonomy.

In order to investigate the effects of the social standing that “family” has, I will explore the idea of the family as a social institution; one that defines its own norms, roles and practices. In particular, I will illustrate how the relatively new focus on “family-centered” healthcare, contributes to underplaying the role and perspectives of child patients.

Public institutions that deliver health care are loath to interfere with the internal politics of families and in fact, have been keen to expand concern for their patients outwards to encompass the entire family. The importance placed upon family has actually led to the development of a new model of health care delivery referred to as, “Patient and Family-Centered Care” or sometimes just “Family-Centered Care.”

“Patient-and family-centered care (PFCC) is an innovative approach to the planning, delivery, and evaluation of health care that is grounded in a mutually beneficial partnership among patients, families, and health care professionals.”[175] Although it should be obvious why such an approach is beneficial when the patient is a child, the approach may in fact be used for patients of all ages.

> PFCC ensures the health and well-being of children and their families through a respectful patient/family-professional partnership. It honors the strengths, cultures, traditions, and expertise that all members of this partnership bring to the relationship. PFCC embraces the following concepts: (1) we are providing care for a person, not a condition; (2) the patient is best understood in the context of his or her family, culture, values, and goals; and (3) honoring that context will result in better health care, safety, and patient satisfaction.[176]

While the benefits of parental involvement in their child’s health care is undeniable, and respect for family-culture as well as ethnicity and cultural traditions is central to the development of any trusting patient-family-physician relationship, family-centered care can actually contribute to underplaying the

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[175] O'Malley, P., K. Brown, *et al*. (2008). "Patient - and Family - Centered Care of Children in the Emergency Department." Pediatrics **122**(2): e511-e521. p. e511.

[176] O'Malley *et al.* (2008). p. e511.

child's perspectives, needs, and decision-making role. For example, in their article, "Parental Involvement and Family-Centered Care in the Diagnostic and Treatment Phases of Childhood Cancer," Holm *et al,* define family-centered care as; "a model of health care delivery that emphasizes providing information, giving parents control over decision-making, and respecting and supporting parents."[177] Note the lack of any reference to the child, on this interpretation.

Holm *et al* researched parental perceptions of their role as participants in their children's health care. Their results identified that,

> Advocacy was the overarching theme that emerged to describe how parents participated in their children's medical care. Advocacy is defined as parents speaking and acting on behalf of their child, as an intercessor and champion, to ensure that their child's needs are met.[178]

Aside from the fact that the researchers defined *advocacy* as "parents speaking and acting on behalf of their child," the parents also seemed to think it was their role to speak for their children. For example, one mother explained to the researchers, "You're your child's only advocate. You've got to stay on top of it. You have to explain, because no one knows what your child is feeling or going through."[179] Note the clear assumption that it is part of the parent's role to express the child's perspective.

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[177] Holm, K., J. Patterson, et al. (2003). "Parental Involvement and Family-Centered Care in the Diagnostic and Treatment Phases of Childhood Cancer: Results from a Qualitative Study." Journal of Pediatric Oncology Nursing **20**(6): 301-313. p. 301.

[178] Holm *et al.* (2003). p. 304.

[179] Carnevale, F. A., E. Alexander, et al. (2006). "Daily Living With Distress and Enrichment: The Moral Experience of Families with Ventilator-Assisted Children at Home." Pediatrics **117**(1): e48-e60. p. e57.

Parents identified four main advocacy roles, all of them clearly important.

> Parents expressed four main strategies of advocacy during the treatment phase: (a) informing themselves about their child's medical status and needs, (b) deciding about their child's medical treatment, (c) limiting medical procedures for their child, and (d) affirming their child's medical professionals [by intentionally supporting and fostering relationships with medical staff].[180]

However, I believe that part of the parental role in the context of participating in their children's health care should also include fostering the skills necessary for the children to assume the decision-making role in the future. Sadly, the parents in Holm *et al's* study failed to recognize any such role or duty.

One mother who participated in Holm *et al*'s study actually suggested to researchers that "medical staff explicitly tell parents that they are members of the medical team and outline for them their role as parent members of the team."[181] Although she was speaking in the context of the decisions she would be expected to make, perhaps this is a worthwhile and simple exercise that physicians should adopt when they are first establishing a relationship with a family that they will be working closely with.

Physicians, who work with children facing illness every day, are obviously more aware of the medical guidelines encouraging pediatric autonomy, the trend to involve children in their health care, and the benefits such involvement can have. Parents, who must initially assume the role of health care decision-maker, often in a time of crisis, cannot be expected to consider how to foster autonomy in their children under these initial circumstances. However, parents have proven to be somewhat reluctant to relinquish that role as their child matures and gains

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[180] Holm *et al.* (2003). p. 307.
[181] Holm *et al.* (2003). p.311.

illness experience. Here, physicians could help guide parents towards the inclusion of their children in medical decision-making from relatively early on.

The Canadian Paediatric Society (CPS) seems to caution against the very offshoot of "family-centered care" that I am addressing here, in its position statement on treatment decisions for children. It reminds professionals that "although family issues are important and must be considered, the primary concern of health professionals who care for children and adolescents must be the best interests of individual children and adolescents."[182] Furthermore, the CPS asserts that, "cultural norms or family values may underlie some parents' reluctance to discuss the child or adolescent's condition, diagnosis or prognosis in his or her presence. While parents' views regarding disclosure are important, the child or adolescent's desire or need for information should remain paramount."[183]

In the context of dealing with adults, Beauchamp and Childress assert that,

> Health professionals should always inquire in general terms about their patients' wishes to receive information and to make decisions, and they should never assume that because a patient belongs to a particular community or culture, he or she affirms that community's worldview and values.[184]

However, child patients cannot be so easily divorced from the family culture in which they find themselves. Carnevale *et al,* explored the moral experience of families caring for children dependent upon artificial respirators at home. This team of researchers used semi-structured narrative interviews conducted in the families' homes, and sought to explore the "moral phenomena inherent in (1) the individual experiences of the ventilator-assisted child, siblings,

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[182] Bioethics Committee, Canadian Paediatric Society. (2004). p. 99.
[183] Bioethics Committee, Canadian Paediatric Society. (2004). p. 101.
[184] Beauchamp, T. and J. F. Childress (2009). p. 107.

and parents and (2) everyday family life as a whole."[185] By "moral" phenomena, the researchers referred to "whatever phenomena the participants themselves considered "right or wrong,""[186] and a large focus of their paper was to explore the moral aspects of the decision to care for the child at home, and the subsequent experiences and moral dilemmas they faced in their daily lives.

Despite the attempt to examine a topic in which the children were expert and in the context of their everyday lives, Carnevale *et al*'s investigation revealed little about the moral experiences of the actual children. The researchers admit: "it was remarkable that we had difficulty getting direct private access to many children, as most parents (but not all) preferred for child interviews to be conducted with the entire family."[187]

Furthermore, in the section of the paper devoted to the results garnered from the interviews meant to elicit the voice of the child, Carnevale *et al* again note that, "the children in this study, both patients and siblings, were generally silent when asked to talk about their experience."[188] The subsequent results of the investigation found in that section are parental expressions of their child's assumed feelings and experiences. In a few cases, the parents shared specific comments that their children had made, which they felt reflected their child's experience. Carnevale *et al*, suggest four possible reasons for the children's relative silence:

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[185] Carnevale *et al*. (2006). p. e48.
[186] Carnevale *et al.* (2006). p. e49.
[187] Carnevale *et al.* (2006). p. e59.
[188] Carnevale *et al.* (2006). p. e56.

> Did this silence mean that (1) these children were genuinely content and had no particular malaise to talk about, (2) they were socialized into the family's "official policy' that everyone in the family was to think positively and do their best to make things work, (3) these decisional matters exceeded the children's mental capacities, or (4) these children's experiences were beyond the realm of verbal articulacy – that they did not have words to express their unique experience? [189]

In response to Carnevale *et al*'s study, Reverend Donald Meloche, Director of Pastoral Services at the Montreal Children's Hospital, an institution of the McGill University Health Center where all the researchers were based, analyzed the children's silence in terms of "important methodological considerations that may limit children's disclosures in the context of research."[190]

Meloche agrees that the second explanation for the silence of the children offered by Carnevale *et al*, i.e. that the children are socialized into the family's official policy, is highly plausible, but gently chastises the researchers for having "no specific provisions for gathering data from children"[191] and for the relative lack of individual interviews conducted with the children alone. Meloche highlights that,

> The reality is that the children did not really have an opportunity to share on their own and outside the presence of those who tend to speak for them. How could they for example express deep distress or desperation, profound sadness or possibly feelings of anger at God for their situation, or anger at their doctors or even at their parents in such a setting? Their dependency on their families, especially their parents, and their need to protect them and to make the best of it would likely prohibit any such expression of feelings.[192]

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[189] Carnevale *et al.* (2006). p. e58.

[190] Meloche, D. (2006). "Listening to the Voice of the Child: Methodological issues involved in conducting research with children." Pediatric Intensive Care Nursing **7**(2): 11-17. p. 11.

[191] Meloche, D., (2006). p. 13.

[192] Meloche, (2006). p. 13.

While Meloche concentrates on what he terms “methodological” considerations to explain the children’s silence, their silence can also be explained sociologically. As described above, children’s abilities to communicate honestly and effectively can be hindered by powerful social forces that are not always obvious, in this case, the social institution of “family” that espouses certain social norms and roles that constrain the children.

Meloche concludes that this design flaw in the study is in fact a happy accident; “for had the study not revealed the extent of the silencing of the voice of the child we might never have known just how little voice the child has in his own care and how little opportunity he has to share what he experiences with others, even with his own family.”[193]

I have revealed that by focusing on family-centered care, the pediatric patient’s perspective can be further minimized and their voices silenced. While it is not my aim to argue against the family-centered care approach in general, I have argued that the primacy accorded to the social institution of “family” makes it difficult to call into question the organization, roles, and powers accorded to its members. By shifting the focus from the patient to the family, the child’s role within the patient-family-physician triad risks being further trivialized, and the child patient’s participation in her own health care can once again be overshadowed by adult interests and agendas.

Health care providers need to become more attuned to how the professional and ethical obligations owed to all patients in the context of health

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[193] Meloche, (2006). p. 16.

care, continue to be subverted by social forces that may be hard to recognize, question, or overcome in the context of pediatric healthcare.

Susan Dodds argues that health care professionals indeed do have a role to play in fostering the development of autonomy in patients who are not fully so, including pediatric patients.

> Encouraging children with long-term illnesses to participate in decision making, to ask questions about their care, to voice their feelings and desires, and to take responsibility for aspects of their own care help them in the development of autonomy competency. On the other hand, uncritically treating such children as ill, needing total care, and unable to understand or accept their condition robs those children of the opportunity to develop the skills needed for autonomy competency. [194]

Like Dodds, another Canadian Paediatric Society's position statement entitled "Transition to adult care for youth with special health care needs," claims that: "The child should be given increasing levels of responsibility and information as they enter adolescence. As youth move closer to the age of transfer, professionals have the opportunity to provide developmentally appropriate information, and to teach skills of negotiation and communication required in the adult system."[195] However, there is no mention of any duty on the part of health care providers to attempt to foster decision-making skills or the development of autonomy in children, only the recognition that professionals have the *opportunity* to do so. The next section will examine the opportunities that health providers have to foster autonomy in their pediatric patients and establish why they have a duty to do so.

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[194] Dodds, (2000). p. 227.

[195] Adolescent Health Committee, Canadian Paediatric Society, (2007). "Transition to adult care for youth with special health care needs." Paediatric Child Health **12**(9): 785-788. p. 786.

Fostering Autonomy:

In the previous sections, I established that social forces can undermine pediatric autonomy. I focused my argument on how these forces silence the voices of children and how their silence hinders the development and exercise of their autonomy. Although these forces can be insidious because they are the result of accepted social norms and practices, on a more positive note, their identification offers a clear direction for improvement and suggestions for how to help foster autonomy skills in children.

One mother involved in Carnevale *et al's* study on the moral experience of technology dependent children and their families, seemed to recognize that she had missed an opportunity to foster autonomy in her physically disabled sons.

> I think one of the biggest mistakes we made from the beginning with this whole thing was that we did all the talking for them. We made all the decisions for them. We didn't really give them much choice in anything. And just later, in the last couple of years now we started realizing they're not infants anymore. Because in my mind they're still little boys. They're adults now, and it's time to start letting them make the decision. And I told them, from now on it's your body, you decide what you want to do. If you don't want something to happen to you, you have the right to say no.[196]

This statement harks back to old-fashioned notions of age-based theories of childhood development. Ironically, although this mother admits that both her children have little experience making decisions for themselves, she believes that since "they're adults now... it's time to start letting them make the decision." Her statement implies a failure to recognize that autonomy skills are progressively learned.

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[196] Carnevale *et al*. (2006). p. e57.

Despite theoretical posturing to the contrary, I believe many health care providers also still rely upon age-based theories of development that obscure any duty they might have to foster autonomy skills in young children. Helen Rushforth's paper, "Practitioner Review: Communicating with Hospitalized Children: Review and Application of Research Pertaining to Children's Understanding of Health and Illness," argues that providing children with appropriate information builds their knowledge and enables them to develop an understanding of even complex illnesses. She explains that new studies seeking to overturn age-based stages of development argue that,

> Only through enabling the child to come to a point of "correct" understanding of what is going on, can misconceptions effectively be eradicated. It is this belief that underpins the more contemporary concepts of health and illness literature, concluding that even very young children have the ability to achieve a sophisticated level of understanding of their illness experience…Through a variety of replications and new research, these studies…recognise that children's understanding can be significantly enhanced by appropriate information giving. These authors urge practitioners to recognise this perspective, and to offer children full, clear, and appropriate explanations which they *are* capable of understanding, and which thus have the potential to reduce their fear and mitigate against the potentially harmful effects of illness and hospitalisation.[197]

Rushforth implies that regardless of age, all children should be given appropriate information that will serve to build the kind of understanding they will need to become competent decision-makers. However, Rushforth's article also hints that appropriate information giving is still not being prioritized in practice.

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[197] Rushforth, (1999). p. 684.

> In a seminal study in 1983 Perrin and Perrin explored United States health practitioners' information giving to children, and concluded that much of this was pitched at "mid school age level", irrespective of the age, cognitive ability, existing knowledge, or previous experience of the child being taught. There is a dearth of contemporary studies in this domain.[198]

In Alderson *et al*'*s* 2006 article, "Children as partners with adults in their medical care," the authors maintain that "adult-child communication tends to be dominated by often misleading age-stage theories and methods, that under- or overestimate many children's abilities."[199]

It would seem that especially in regards to young children, health care practitioners continue to be led by assumptions about children's age-based cognitive skills that preclude attempts to engage children in their health care. Rushforth argues from a rights perspective that,

> It is important to acknowledge that children's rights to voice an opinion is not restricted to issues of formal consent. Giving children choices and an active role in decision making in other aspects of treatment and care is also their right, and may significantly contribute to helping them cope with hospitalisation.[200]

However, it is equally important here to recognize missed opportunities for children to learn negotiation and communication skills, and to develop self-trust. Children can in effect "practice" decision-making in regards to issues of lesser importance than those normally implied by the need for formal consent. Those skills will then serve them well in the future. According to the CPS,

> This can be achieved through the concept of assent whereby children are given both information that they can understand and some appropriate choice in their treatment. An example would be

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[198] Rushforth, (1999). p. 685.
[199] Alderson, *et al*. (2006). "Children as partners with adults in their medical care."
[200] Rushforth, (1999). p. 688.

> to give a child the choice of arm in which to receive an injection, rather than to give a choice about whether or not to receive the injection. This approach subsumes both voluntariness and age-appropriate information, and demonstrates to the child that he or she is respected as an individual. The use of assent also may improve cooperation with treatment, lessen the child's anxiety, enhance the development of trusting relationships with adults, and improve long-term patient-physician relationships. Care should be taken so that children in these circumstances are not given the impression that they have more control than they do.[201]

Perhaps of even greater concern is the fact that as children mature, they are not being included more in their own health care as the Canadian Paediatric Society and Canadian child health law urges. In a study on parental assessments of self-efficacy in medical decision-making for their children entitled, "Toward Family-Centered Inpatient Medical Care: The Role of Parents as Participants in Medical Decisions," Tarini *et al* "did not see an effect of child's age on parental participation despite [their] a priori hypothesis that reported parental participation would be inversely correlated with a child's age."[202] This seems to imply that parents are not withdrawing from the decision-making role as their children accrue illness experience and maturity, and can assume more responsibility for themselves.

Stronger evidence for this is also offered in another Canadian Paediatric Society (CPS) position statement entitled, "Transition to adult care for youth with special health care needs." In it, the CPS explains that,

> Adult health care providers have identified a number of concerns about patients who have transferred from paediatric health care, specifically the lack of adherence to proposed treatment plans,

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[201] Bioethics Committee, Canadian Paediatric Society. (2004). p. 101.

[202] Tarini, B., D. Christakis, *et al*. (2007). "Toward Family-Centered Inpatient Medical Care: The Role of Parents as Participants in Medical Decisions." The Journal of Pediatrics **151**(6): 690-695e. p.692.

> deficiencies in knowledge about the condition and limited self-care skills. These differences may be partially explained by the differences between the mandate and functioning of paediatric and adult services. Paediatric care is family focused, relies on developmentally appropriate care with significant parental involvement in decision-making and prescribes care within a multidisciplinary team. Adult care is patient focused and investigational, requiring autonomous, independent consumer skills without many interdisciplinary resources. Adult health care differs significantly from paediatric care in the type and level of support, decision-making, consent processes and family involvement.[203]

The problems related to the transition from pediatric to adult care identified by the CPS, make it clear; the shift in decision-making responsibility that is supposed to happen as a child matures, is not being consistently applied. However, it is the children who suffer the consequences when they reach adulthood lacking the autonomy skills necessary for self-care.

In his book, *Justice for Children, Autonomy Development and the State*, Harry Adams argues that,

> Autonomy is not an attribute that all adults possess automatically or necessarily, simply in virtue of their being adults (or humans, or moral agents, or citizens, etc.); but rather, autonomy is an attribute that *some* adults come to possess as an ideal end-product of a contingent process of personal development." As such, the moral imperative to "respect others' autonomy,"…only becomes truly valid (truly coherent, complete and properly action-guiding within the context of theories of justice) when understood as the imperative to "respect the possession, but also the *development,* of persons' autonomy.[204]

Adams goes so far as to argue that "it is morally permissible, and perhaps even obligatory for the state to intervene [in the family] on behalf of children

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[203] Adolescent Health Committee, Canadian Paediatric Society, (2007). p. 785.

[204] Adams, H. (2008). Justice for Children: Autonomy Development and the State. Albany, N.Y., State University of New York Press. p. 2.

whose development of autonomy may be seriously arrested or crippled.[205] Adams is speaking of a minimal level of general autonomy, i.e. not related to a specific context such as health care, without the development of which an individual will not be capable of independent functioning.

In the context of pediatric health care, Adams' aggressive approach would be ineffectual, impractical, and even harmful. However, I am sympathetic to Adams' general argument that there is a duty to ensure that children have the opportunity to develop a minimal level of autonomy. In the health care context, this could best be achieved by *engaging* the family in the practice of fostering the development of their child's autonomy.

What if We Sent More Positive Social Messages? :

Children's moral status, the effects of their embodied illness experience and the uniqueness of their individual perspectives demand that bioethical discourse grant children moral consideration. As moral agents, the duty to respect children's autonomous decisions can be premised upon the same foundations as adults; they deserve the opportunity to make choices for themselves that are in keeping with their own personal values and goals. To allow them this opportunity may in fact help them to build self-trust, to make sense of what they are going through, and to direct their care in ways that may be very meaningful to the children. These are all important and valid reasons to encourage the development of pediatric autonomy in the health care context.

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[205] Adams, (2008). p. 3.

This chapter has focused on how the voices of children are silenced by oppressive social cues that send strong messages to children about the nature of their role in the patient-parent-physician triad, the importance of their perspectives, and the value of their participation in health care decision-making on their own behalf. In this section, I would like to offer some possible evidence that sending positive social cues can encourage children to participate more actively in their health care.

As discussed above, one tool that is starting to be used in the pediatric context is that of soliciting "assent." Seeking assent may have a positive effect on fostering pediatric autonomy by ensuring that appropriate explanations of the proposed treatment are given directly to the child, and by sending the message that the child's participation is important. Therefore, assent might not only offer an opportunity to develop autonomy skills but also might demonstrate how sending positive social cues to children about the value of their participation and perspectives, could lead to the development of self-trust and greater levels of autonomy in children.

In an article entitled, "How do Children and Parents Make Decisions About Pediatric Clinical Research?" Varma *et al* interviewed sets of children and their parents from two groups; either the children were enrolled in a research project or they were receiving clinical care for either asthma or cancer. Although the sample size was small, the results were very interesting.

> When asked who should decide whether the child is enrolled in research, the most common answer among the pediatric respondents who were participating in research was that the child alone should decide (33.3%). The least common response was that the parents alone should decide (9.5%). A significant association

> was found between responses to this question and the respondent's age, with children aged 11 to 14 years more likely than those aged 7 to 10 years to say that they should be the primary or sole decision makers (P=0.04). Among adult respondents in the research group, the most common response was that the parents alone should decide (38.5%). Within parent-child pairs, there was no significant association between the parent's and the child's responses to this question (P=0.29) In the clinical care group, the most common answer from both pediatric and adult respondents was that parents alone should make clinical treatment decisions for the child (45.2% and 75.0%, respectively).[206]

First, the significant discrepancy between the pediatric and adult respondents in regards to the children's decision-making role, affirms that parents can fail to recognize the importance of including their children in health care decision-making and miss opportunities to help foster the development of their autonomy.

Secondly, the results showed that the most common answer given by children in the clinical group was to say that parents should be the primary or sole decision-makers for care; however, the most common answer from children in the research group was that the children alone should decide about whether to enroll in research. One possible explanation for the difference in results is that the children participating in research had been asked to sign an assent form.

> All of these children understood signing the form as indicating their willingness to be in the study or as giving their permission to be enrolled. When asked in an open-ended question how they felt about signing the form, responses ranged from indifference ("I don't mind") to endorsement ("Like I was in charge"; "very good"). No child expressed negative feelings about signing the assent form.[207]

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[206] Varma, S., T. Jenkins, *et al.* (2008). "How do Children and Parents Make Decisions About Pediatric Clinical Research?" Journal of Pediatric Hematology/Oncology **30**(11): p. 826.

[207] Varma, *et al.* (2008). p. 825.

By being asked to sign the assent form, children were sent the important social message that they were thought capable of making such a decision and because participation in the research was strictly voluntary, the children understood that their decisions would be respected. For some of the children, signing the assent form may have bestowed a sense of self-trust, as the child who felt like "[she] was in charge," implied. This offers some evidence that sending positive social cues to children can be an effective way to help foster autonomy skills.

It is clear from this section that practical and effective ways to foster autonomy skills and autonomy in children do exist. What seems to be lacking however, is awareness of the important role that social forces play in the development of children's autonomy, and perhaps the motivation and resolve to overcome them. I hope I have provided both here.

Conclusion:

In the introduction to this paper, I said that my goal was to adopt a feminist "relational" approach to autonomy, in order to investigate how social forces affect pediatric autonomy on all three of the levels described by MacKenzie and Stoljar. In this chapter, I established that despite the development of a new sociology of childhood, one that accepts children as competent and autonomous, social forces continue to negatively affect children's autonomy in the context of health care, on many levels. Since communication skills are a necessary requirement for the development and exercise of autonomy, I used communication as a paradigm case, and a relational approach to illustrate how the broader social context within which children's attempts to exercise autonomy is situated, can impede those attempts.

Children's rational and cognitive abilities are but one small part of the pediatric autonomy equation, their embodied experience is also shaped by social cues that adults are not even always aware they are sending and which can negatively influence a child's ability to exercise autonomy, despite sufficient cognitive capabilities.

The particular context of illness and the development of autonomy in health care might actually present additional, specifically relational, challenges for children. For example, parents are perhaps more likely to want to protect and control children, who have already historically been perceived as vulnerable and in need of protection, more so in the health care context, than in, for example, the context of general autonomy development within family life or at school. The context of child illness and health care might imply asking parents to relinquish some control at a time when they are most vulnerable themselves, and when such important decisions need to be made.

Furthermore, the cultural and family background from which a child comes can affect not only the child's opportunities to be autonomous but also, how involved in decision-making the child *wants* to be. Autonomy in health care is a Western Liberal approach that not all cultures share, and not all "Western" families encourage independent thinking and free expressions of children's personal perspectives. Accordingly, many children may neither expect nor wish to be heavily involved in decision-making regarding their health, a fact that proponents of relational autonomy are well suited to appreciate.

Of course, my intention here is not to force unwilling children to make autonomous health care decisions for themselves, but only to argue that children who wish to take on a more substantial role in terms of their health care should be encouraged and allowed to do so. Bioethics cannot in good conscience, continue to uphold a discourse and practice that has been shown to oppress children as a group, in such significant ways.

The relational approach I adopted has demonstrated that pediatric autonomy can be hindered by the social framework within which it is practiced. Therefore, rather than continuing to focus on the competencies of children, supporters of pediatric autonomy should perhaps shift focus to examine the social structures and context within which children's attempts to develop and exercise autonomy are frustrated. While it has been shown that parents tend to silence their children by speaking for them, they could assume an important role in fostering the development of autonomy skills, if that role were made clearer to them.

I firmly believe that the onus is on health care professionals to guide parents towards understanding why pediatric autonomy is an important skill to develop. By structuring the patient-parent-physician triad and the family-centered care approach in such a way as to elicit the voice of the child and affirm the child's role in their own health care, health care professionals could significantly increase children's opportunities to develop autonomy skills.

Conclusion:

The new importance placed upon pediatric autonomy in bioethical discourse is often constrained by the tension between wanting to respect pediatric autonomy and wanting to protect children from harm. Although respect for autonomy is not absolute in bioethics, significant justification is required in order to deny adults respect for their autonomy. While an obvious lack of understanding or rationality on the part of an adult can be sufficient grounds for such a denial, children such as A.C. can have respect for their autonomy denied with no such justification at all.

The evolution of bioethical discourse in relation to children and their autonomy has been held back by old-fashioned notions of children, their abilities, and the historical mandate that bioethics adopted: to protect "vulnerable" and "passive" children from harm. Unfortunately, since bioethical discourse has not evolved at the same pace as our social perspective of children, it no longer reflects an appropriate image of children nor adequately responds to their current needs or interests in the health care context. Given the evidence I have presented here, bioethical discourse cannot allow age alone to provide sufficient justification for failing to allow children to participate in their health care, failing to provide them with clear information about their illness and treatment plan, or for denying their autonomy.

I established the moral status of children and offered evidence that many children with illness experience are capable of a level of competency in medical decision-making that rivals that of adults. I argued that this moral status demands equal treatment for children in the context of health care. Although I examined current Canadian medical guidelines and legal principles that are consistent with the new sociology of childhood, I also cited the Supreme Court of Canada case, *A.C. v. Manitoba (Director of Child and Family Services)* as an example that in practice, adults can simply refuse to respect children's autonomy.

Since the need to respect pediatric autonomy in the health care context has gained acceptance in theory, but remains easily subverted in practice, I adopted a feminist approach to bioethics to analyze this trend. I uncovered that social forces can oppress a child's ability to develop and exercise autonomy on all three of the different levels identified by MacKenzie and Stoljar, by showing how these forces act to silence the voices of children in the health care context.

So why *did* the Little Mermaid stop singing? The answer that I provided to this question in my introduction was that she gave up her voice in order to respect the social norms of the humans, to fit in, to be accepted. While my answer may have seemed far-fetched, even extreme given the method of her silencing, its plausibility has now been substantiated. Children in the health care context remain silent every day for the very same reasons. The desire to respect social norms is a powerful motive that we should not underestimate; this was evidenced by the children in Bluebond-Langner's study who suffered the fear and uncertainty of their impending deaths in silence, to avoid breaking a social taboo.

While A.C.'s voice was blatantly "silenced" by Kaufman J's refusal to include her in the court proceedings, other more surreptitious but equally powerful social forces can be more difficult to recognize, because they are embedded within our accepted social norms and practices. Therefore, the very social forces that need to be overcome can also operate to legitimize practices that oppress pediatric autonomy. Given how hard it is to recognize the social forces at play, it is imperative that children be given the tools to develop the autonomy competencies necessary to find their voices and combat their own oppression. As McLeod explained, "having trustworthy professionals is not a solution on its own to patient vulnerability. An important additional element is respect for patient self trust.[208]

If children indeed enjoy a moral status on par with adults, then bioethics owes children the same duties as adults in terms of respect for their autonomy. One of those duties is surely to ensure that children, as a group, are not systematically oppressed by existing bioethical practices. Therefore, I believe that health care professionals have an undeniable duty to help all children become autonomous in the health care context.

I am certain that continued investigation into how social forces can hinder pediatric autonomy would uncover many other examples; however, by uncovering the social tendency to silence children, I have at least revealed one practical area upon which an attempt to foster and support pediatric autonomy can be focused. Physicians and other health care professionals who work with children have the opportunity to adjust their practices in light of the analysis I have presented here. They could help foster the development of the skills necessary for autonomous decision-making, and better respond when children demonstrate autonomy.

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[208] McLeod, C. (2002). p. 1.

> There should be a greater recognition of the diversity that exists amongst children with respect to their capacities. The perception of the child as a vulnerable individual has been the metric for regulation and legislation, and is precisely the paternalistic presumption that should be challenged. It is important to establish that children are not a single, homogenous group.[209]

In part, this will mean that health care professionals will need to focus on individually assessing each child's understanding, abilities, and willingness to participate in their own health care, and react in kind. Fostering the development of the skills necessary for autonomy should become a priority for health care providers, regardless of the child's age. Canadian law could support this practice by removing the legal age of consent from the legislature with the aim to encourage this kind of individual assessment for all children. If a child's capacity to give consent were assessed at each opportunity, in the same way that bioethics practice now demands an individualized assessment for adults whose autonomy is questioned, children would be afforded many more opportunities to practice exercising their autonomy, to receive reliable feedback, and to develop self-trust.

Physicians can also make a point to engage parents in the fostering of children's autonomy by informing them of the importance of including children in their health care and by setting a good example. In order to do this, physicians should heed the advice of Dr. J. Plant who wrote a short commentary entitled "The Pediatrician and his Patient," in the fourth edition *Textbook of Pediatrics*, published in 1945. In it, Plant cautioned that, "the pediatrician cannot anxiously tell the parent to be calm, or hurriedly tell the child to be patient…So with the

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[209] Haggar, (2009). p. 183.

child (and parent) it is in the way that we talk, stand, walk, give advice that we transmit our most important messages."[210]

It is time to take this insightful message from the past to heart. Health care providers need to become more aware of the social cues they send to children in their interactions with them. In order to support this claim, I provided some evidence that sending more positive social messages to children can foster communication and autonomy. Some simple but helpful practices might include: giving the child complete information using appropriate language; encouraging the child to voice their questions or concerns, alone to the physician if necessary; treating the child's opinions, perspectives or statements with importance and respect; advocating for opportunities for the child to have her voice heard and her wishes respected whenever possible; being watchful for oppressive social forces that can be overcome and encouraging parents to adopt a similar approach.

Although recognition and respect for children's autonomy claims has come a long way, social forces that oppress children's opportunities for autonomy are particularly insidious because they are cloaked in entrenched social norms and practices that we rarely think to question. More investigation into how oppressive social forces frustrate pediatric autonomy will obviously be needed. It is my hope that in the meantime, health care providers will accept their duty to foster autonomy in their child patients in order to prepare them to become capable, self-governing individuals. Such an approach might eventually lead to full respect for autonomous children and their choices.

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[210] Plant, J. (1945). The Pediatrician and his Patient. Textbook of Pediatrics, Fourth Edition, Revised. W. E. Nelson. Philadelphia, W.B. Saunders Company**:** 11-12.

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