CHRONICALLY AND TERMINALLY ILL CHILDREN AND MEDICAL DECISION-MAKING

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ABSTRACT

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This thesis is an investigation of the traditional philosophical and legal positions regarding the status of children. I argue, contrary to that position, that under certain circumstances children can make medical decisions pertaining to their own care. Specifically, I argue that chronically and terminally ill children above the age of six generally have developed skills and capacities pertinent to autonomous decision-making. Because of their familiarity with the factors that contribute to their care and well being, these children should be considered to be "experts." Moreover, I argue that it is experience more than chronological age that contributes to autonomy, and that subsequently all children over the age of six ought to participate in decision-making to some degree. Finally, I present an approach for us in clinical practice that I argue will reconcile the needs and abilities of chronically and/or terminally ill children with responsibilities or parents as set forth in theory and law.

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With much pride and satisfaction I dedicate this work to my grandmother, Ilonka Rodak-Izso (z"l), who thought of me always... and thinks of me still.

Rina S. Rodak

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INTRODUCTION

When children get sick, treatment decisions about their health care must be made. Generally, when an adult falls ill, she is permitted to make decisions pertaining to her own care. The same cannot be said in the case of a child. The traditional philosophical position with respect to children presumes that children are not fully rational beings because their actions are ruled by emotion and not by reason. Such a presumption causes a dilemma with respect to the ethical treatment of patients who cannot consent on their own behalf.

In light of children's moral status, someone who is fully rational must make decisions on their behalf. The traditional philosophical position insists that the decision-maker ought to be the child's parent or parents. This is because parents are usually their children's primary caregivers, role models, and safety-providers. Such an approach raises a number of issues, all focusing on the potential for conflicting interests and conflicting responsibilities.

The purpose of this thesis is to explore the issue of children's participation in the making of decisions about their own care. The discussion will focus on the moral status of children, the role of parents, and subsequently, how decisions pertaining to children ought to be approached.

The motivation to explore this issue arose out of my own experiences with children and parents. Having witnessed many children make moral choices, I began to question the traditional position that children cannot make fully rational choices. Having witnessed many a parent conflate her own best interests with those of her children, I began to question the traditional philosophical position regarding parents. Furthermore, having worked with families in which a child is seriously ill, I began to suspect that a reformulation of the philosophical position regarding the moral status of children was very much needed.

This philosophical exploration challenges the traditional philosophical and legal position regarding the status of children. I argue that contrary to that position, that under certain circumstances children can participate in the making of decisions pertaining to their own care, and moreover, that all children ought to participate in the making of such decisions, though to different degrees.

This thesis is divided into four sections. Section 1 contains 4 subsections: *Subsections 1.1* and *1.2* include a review of the traditional philosophical position with respect to children and to parents. The implications of these positions are examined in *Subsection 1.3*, and finally, the entrenchment of the traditional positions in Canadian law is included as *Subsection 1.4*. Section 2 consists of an in-depth critique of the traditional philosophical positions, focusing on problems with the traditional philosophical assumptions about experience and on potential conflicts of interests. Section 3 establishes a revised moral position. Finally, the objective of Section 4 is to complement the revised moral position with recommendations for application in a health care environment.

The term "parent" actually has two senses. It can refer to one's biological relation or, for the purposes of this thesis, can refer to one's moral relation. This includes one's commitment, responsibility, and intention towards one's child. In this sense, the label of "parent" is earned through on-going, long-term action. Traditional philosophy defines "child" as a person who is biologically, ethically, and politically immature. The bulk of this thesis focuses on children between the ages of 6 and 12 who are chronically and/or terminally ill. The phrase "fully participate" is intended to include participation of the agent to the fullest degree. In other words, the agent represents her own interests in all levels of discussion and deliberation, and finally, reaches a decision with respect to those interests on her own behalf.

CHAPTER I

THE TRADITIONAL PHILOSOPHICAL POSITIONS

The appropriate place to begin this thesis is the traditional philosophical position regarding the moral and political status of children and parents. For the purpose of fair explication, I have chosen three influential political philosophers, each from a different philosophical era, who have written about children and whose views characterize the traditional position. For the sake of organization, I will first outline the traditional view regarding children, and will then attend to the view on parents separately.

1.1 TRADITIONAL PHILOSOPHICAL VIEW REGARDING CHILDREN

In general, the traditional philosophical view regarding children is that children are not rational beings. It is believed that children are cognitively immature and that they lack experience and opportunity. It is with time and guidance that each child reaches adult maturity.

1.1.1 Aristotle:

Aristotle does not speak specifically about the philosophical status of children. In order to understand the Aristotelian position on children one must rely upon the occasional remark on related themes, such as child rearing.

From these related themes it is possible to establish that Aristotle considers children to be biologically, ethically, and politically "unfinished" relative to an adult.[1] The human child is an ever-changing substance, growing and developing to adult completion. Within this substance is a progression with distinct phases, each with its own *telos* (understood as an end or goal).[2] These developmental phases build upon one another, forming a series of linked goals. Moral development only moves forward once a certain degree of biological development takes place and political development begins only once a degree of moral development is completed.

In *Nicomachean Ethics*, Aristotle asserts that the chief attribute of growing children is that they are "guided by feeling" rather than reason and experience.[3] Because the faculty responsible for deliberation is not yet developed, they are not guided by reason, and children are seen as incapable of rational choice. Ethical maturity is only developed through the guidance of reason, cultivated through the repeated exercise of restraint and virtuous conduct.[4]

Although further discussion of the Aristotelian position regarding parents appears in paragraphs that follow, it is helpful to include here that Aristotle allots the responsibility of primary role model and educator to parents.[5] He explains that the nurturing and discipline that parents assert directly influences the child.[6] In Aristotelian terms, "nurturing" is understood as the providing of affection, shelter, and sustenance for the child and "discipline" is understood as the continuous discouraging of action rooted in emotion.[7]

1.1.2 John Locke:

In *Some Thought Concerning Education* (*1693*), Locke describes children as "travellers newly arrived in a strange country, of which they know nothing."[8] They are strangers, so to speak, because they lack knowledge and moral sense. Children require education since they must be taught to reason in order to become full members of this country.

Locke explains that children are fledging but imperfect reasoners. He says children understand the difference between right and wrong as early as they understand language. Children are born with an innate ability to override emotion with logic. With age and experience the ability is exercised and developed to maturity.[9] Locke asserts that the human mind at birth ought to be thought of as "white Paper, void of all Characters, without any Ideas."[10] The mind is supplied with ideas from both direct sensory awareness and reflective awareness of the mind's own operations.

Similar to the Aristotelian view, the Lockean view is that children are able to recognize rational options, but they are overwhelmed by irrational inclinations.[11] Children must be cajoled and induced into the rational mastery of their desires. In Lockean terms, free action is action only in accordance with the law of reason.[12] Whoever lacks reason thereby lacks the means to make free choices. Because children lack reason they are incapable of making decisions that promote their safety and encourage development.

Despite their inability to act freely, Locke does concede that children have needs and interests. He stresses that children should be reasoned with and not simply physically or mentally coerced into conformity with rules of required behaviour.[13] Furthermore, he says that children ought to be treated as potentially rational creatures because mature reasoning is only developed with age.[14] He explains that as children "grow up to the use of reason, the rigour of government," may be "gently relaxed."[15] Children do not simply broaden their range of experiences and, as a consequence, have more to reason about. Instead, their abilities to reflect upon the inner workings of the mind grow with time.[16] Adults, says Locke, do not differ significantly from children in basic cognitive abilities, but have had more time in which to reflect, as well as more material upon which to reflect.[17] As children are exposed to new ideas, their mind awakens; it "thinks more, the more it has matter to think on."[18] "The use of Reason becomes daily more visible, as these Materials, that give it Employment, increase."[19]

1.1.3 John Rawls:

Like Aristotle, Rawls pays little attention to the moral status of children. He does, however, provide a philosophical account of the development of moral reasoning in children. The Rawlsian conception of moral development in children has been likened to that introduced by 20th century psychologists Piaget and Kohlberg. Such a comparison has been made due to Rawls' stage-based approach to moral development, the specifics of which are comparable to those proposed by the two aforementioned psychologists.

According to Rawls, child-agents normally go through three distinct stages in their moral development: "the morality of authority,"[20] "the morality of association,"[21] and "the morality of principles."[22]

At the beginning of the first stage, the morality of authority, the child is helpless and completely dependent on adults for her very existence and for guidance regarding the intricacies of the world.[23] At this point in development, the child has no basis upon which to question the injunctions of parents or other adult caregivers. Rawls holds as an ideal assumption that all children are loved by their parents. He postulates that a child who is loved will respond with love. Thus, the child comes to trust her parents because she recognizes that the person upon whom she depends does in fact love her. This trust strengthens her tendency to respect and obey the commands of the parents, presumably because she comes to realize that the parents' commands are in her best interests. Because of this, the child desires to be like her parents.[24] Eventually, when the child disobeys her parents' commands, she will feel guilt at having disappointed her parents, whom she loves. During this first stage, the content of the child's morality is just a collection of her parents' commands. From the child's point of view, these commands seem arbitrary and are obeyed solely in an effort to please and to be liked by her parents.[25]

As children enter into the second stage, the morality of association, "they acquire... attachments when others of longer standing membership do their part and live up to the ideals of their station."[26] Bonds of mutual trust and friendship, developed as a result of constant interaction between child and other children and adults, build these attachments. Most simply, this stage is marked by the child's realization that the rules of morality make cooperation and mutual benefit possible.[27]

Initially, the child is unable to understand the interconnectedness of human action.[28] She is unable to recognize that her actions and decisions affect other people and other people's decisions. The role models arouse the child's innate desire to imitate.[29] As a result, the child further internalizes the standards exemplified by her parents. Rawls argues that certain cognitive skills, those necessary for an individual sense of morality, are also developed through imitation.[30] This is because imitating involves the child learning the view of the world from the perspective of other people.

The third and final stage, the morality of principles, involves the generalization of the sense of morality acquired in the second stage. The child comes to desire her compliance with moral principles purely out of respect for them as principles and less because of "ties of friendship and fellow feeling for others, and... concern for the approbation of the wider society."[31] Rawls further explains that "we develop a desire to apply and to act upon the principles of [morality] once we realize how answering to social arrangements has promoted our good and that of those with whom we are affiliated."[32]

Common to the above accounts is an emphasis on the direct role of parents in their children's development. In the following sub-section I will outline the traditional philosophical view regarding parents as represented in the works of Aristotle, Locke, and Rawls.

1.2 TRADITIONAL PHILOSOPHICAL VIEW REGARDING PARENTS

In general, the traditional philosophical view regarding parents asserts that they are their children's primary caregivers. Part of the role of primary caregiver is to act as appropriate role model. As their children's primary role models, the decisions and behaviour of parents in regard to their children ought to be ethically exemplary.

1.2.1 Aristotle:

In Aristotelian terms, a child's potential for reaching maturity resides in her exposure to the maturity already developed by her role models. As adult persons, parents have achieved the level of maturity that the child will develop over time. The potential to guide their child to ethical maturity exists in parents' virtuous activity in relation to that child.[33] In this way, the linkage between parent and child can be likened to that between a cause and its effect. The child's behaviours are a result of the behaviour modeled for her by her parents.

Parents assume the responsibility of the child's ethical guidance and formation because their own deliberative faculties are mature, and because they have sufficient experience of life. Parental authority and competence are justified by their already mature ability to displace emotion with reason. According to Aristotle, the family is taken as a natural unit and the on-going relationship between parent and child is also natural.[34]

Children are friends with their parents, though they are unequal ones. This inequality is due to parents' superior biological, ethical, and political maturity.[35] Nonetheless, Aristotle describes the ethical relationship between parents and children as a true "friendship."[36] As he explains, the relationship between friends involves associating together and sharing a life, well wishing, and behaving kindly towards a particular other.[37] Aristotle suggests that maternal attitudes, in particular, exemplify these features.[38]

Aristotle explains that parents love their children as "other selves."[39] This is not to say that parents see their children as mirror images of their own virtue, but that children are extensions of the parents' own virtuous activity. Children should not be understood as identical to or one with their parents, but as part of their parents in the same way the branches of a tree are part of the trunk and the roots. Without the trunk or roots the branches of a tree would not grow. If water and nutrients are properly passed through the roots of the tree, then the branches will flourish and, in turn, give rise to leaves. If the necessary nutrients are not passed through the roots properly, then the branches will whither and remain undeveloped. Similarly, children flourish when their parents provide them with virtuous behaviour upon which to feed and imitate.

1.2.2 John Locke:

Locke believes, as Aristotle does, that parents ought to have full authority over their children. This authority is grounded in a child's lack of reason and subsequent inability to care for herself. Locke qualifies this claim by noting that exercise of parental authority ought to be proportionate to the degree of the child's lack of reason.

In Lockean terms, parents have a "sort of rule and jurisdiction"[40] over their children, albeit a temporally restricted one. The nature of children justifies parents in acting on their behalf. However, the nature of children also demands whatever tutelage is necessary for the child's development. Locke argues that parental obligation stems from an antecedent right that children themselves possess. Nobody has rights over a child simply on account of being her biological parent. As Locke says, parental power does not belong to parents by any natural right, but only because parents take on the responsibility of guardians.[41] Parental rights are, therefore, not ownership rights. For Locke, parents may very well be naturally disposed to act in the interests of their children and they may very well be bound to their children by natural ties of affection.[42] Parental power is derived from one's actions, and it is limited by the duration of the child's state of minority.

1.2.3 John Rawls:

In the third part of *A Theory of Justice*, Rawls discusses moral development, and subsequently he discusses the role of parents.[43] He further discusses the relationship shared by parents and their children in his discussions of inheritance[44] and legitimate authority.[45]

Rawls assumes that "the child comes to love the parents only if they manifestly first love him."[46] Once the child recognizes the love her parents hold for her, she will become more obedient to their commands as a sign of reciprocating their love. According to Rawls, the development of such an association is the key to the child's overall development, particularly the child's understanding of justice.[47] Without these feelings of love, the child will not feel guilty about disobeying her parents' rules or social rules.

Rawls says little about the nature of child rearing. He does, however, make a statement about the importance of parents to their children's overall development. A child's sense of justice as well as their moral identity depends upon that first bond formed between parent and child.[48] Before the child can proceed to form bonds of trust and reciprocity with other community members, she must first recognize that her parents love her and act in her best interest based on that love.

1.3 IMPLICATIONS OF THE TRADITIONAL PHILOSOPHICAL POSITION

1.3.1 Children Cannot Fully Participate in Major Decision-Making

To deny that children are fully rational is to deny that children can make major decisions autonomously. In order to understand the consequences of this deduction, the concept and conditions of "autonomy" must be explained in fuller detail.

1.3.1(a) The Concept of Autonomy

Generally, autonomy ought to be understood as the rational rule of self, free from control by, or interference from, certain limitations.[49] In this context, "autonomy" is definable as freedom from undue constraint and as the application of critical mental capacities necessary for knowledgeable, intentional, and voluntary decision-making.

Freedom from inappropriate interference is one of the defining conditions of autonomous action. Though some limitations to and influences on one's choices are appropriate, others are not. A general example of an appropriate limitation is when a person is prevented from stepping into the street when a car or bus is coming. This interference is acceptable because harm is prevented. Though the decision to cross the street at that moment was an autonomous decision, the decision would have been made differently had the person known that car was coming and that danger was imminent. In general, an inappropriate limitation is one that causes a person to make a choice that typically, she would not make based on the fact that the consequences of that choice violate her personal system of values and reason. For example, a robber puts a gun to the head of her captive and forces the captive to choose between dieing himself or killing another to save himself. Such behaviour is morally unacceptable on many levels. However, this scenario is inappropriate in the context of autonomous decision-making because the decision-maker's own sense of what is right and wrong is replaced with reasons imposed by the robber. If the gun and the threat of his own death were removed from this situation, then the captive would not choose to kill another person. It is the imposed circumstance that inhibit.

In a more specific context such as medicine, an example of an appropriate limitation is when a physician explicitly recommends that a patient pursue a second opinion from a more specialized physicians or reveals that a different health care facility may have greater more treatment possibilities. Such a situation could arise in smaller communities where immediate resources are limited. Recommending that a patient withhold her decisions until all avenues are pursued is appropriate because the health care worker is helping the patient to expand her knowledge of available and accessible treatments. This can only help the patient to make a more informed decision about her treatment plans. An example of an inappropriate limitation in a medical context is when a health care provider withholds information about certain treatment options or makes certain treatment recommendations based on her own benefit, rather than that of her patient. This might occur if the health care provider is directly involved in research with or the development of a specific treatment, and therefore stands to gain directly from the use of this treatment over another. Limiting a patient in this way is inappropriate because the patient is not permitted to equally weigh all the potential treatment options. Instead, she is influenced by her healthcare worker's personal bias.

Exercise of rational self-control is also a defining condition of autonomous action. Typically, inclinations based on emotion must be superseded by those based in reason. The agent's priorities and reasons ought to be based on logic and typically, not on feelings of guilt, anger, or on the quest for happiness.

An example of the exception, in which emotional motivations are appropriate, is when one buys a red sweatshirt instead of blue sweatshirt simply because of a preference for the colour red. This is appropriate because the function of the sweatshirt remains the same regardless of its colour. It is a bonus that the colour of the sweatshirt allows the purchaser to enjoy the sweatshirt more than if it was another colour. Decisions based in emotion become inappropriate when considerations of logic and reason are ignored in order to honour one's quest for happiness. For example, if the red sweatshirt costs $100 more than the blue sweatshirt, then we might conclude that the purchaser's quest for happiness has superseded reason or logic. Though the colour of the sweatshirt pleases the purchaser, its price compromises the purchaser's future purchasing power. She might not be able to afford groceries or other necessities if she chooses to buy the red sweatshirt over the blue one. In this case, it is emotion's inhibiting of reason that renders its motivation inappropriate.

Conformity to the above conditions shows others that the person recognizes herself as intrinsically valuable and has developed the abilities to represent her interests accordingly. Recognition of the agent's ability to behave autonomously by other individuals and society as a whole earns the agent the right to behave according to her own volition, free from the involvement of others.

The traditional philosophical position deems children unable to fully exercise any of the capacities necessary to behave autonomously. Because of their degree of biological, ethical, and political immaturity, children are not traditionally thought of as free. For the same reason, children are not though to be capable of rational self-control. According to Aristotle, Locke, and Rawls, children are inherently imperfect reasons, thought to be slaves to emotion, acting upon desire and passion. Because of the degree to which they are influenced by the actions of their parents, children cannot accept responsibility for their actions. The principles upon which children act are learned directly from their parents, and therefore, responsibility for moral decisions pertaining to a child fall upon her parents.

1.3.2 Parents Ought to Make Major Decisions on Behalf of Their Children

The traditional philosophical position claims that it ought to be parents who are responsible for making decisions on behalf of their nonautonomous children. When a person is a parent, they have a unique privilege of being able to choose for another human being. This privilege is not granted in other circumstances. As already explained, parents are responsible for their children's development, including their moral and political development. In the following paragraphs I will show that it is because of this unique responsibility that the traditional philosophers designated parents and not other caregivers as their children's surrogate decision-makers.

Before continuing on to discuss the assumption that it is parents who hold the moral responsibility of making decisions on behalf of their children, it is important to understand the concept of moral responsibility more fully. Without a general understanding of the concept, a clear understanding of the relationship between parents and their children will not be achieved.

1.3.2(a) The Concept Of Moral Responsibility

Moral responsibility consists in assignment of accountability based on the rules of morality. To be morally responsible for the condition of a child is to be in control of, and subsequently, it is to be blameworthy or faulted for, the child and her development (to the degree that biology is not).

Traditional philosophy maintains that parents are morally accountable for the safety and the biological and social development of their children. Biological parents have a moral responsibility to their child even if they are giving the child up for adoption. Finding a suitable environment (or qualified agency who can find such an environment) where the child's full range of needs and interests will be provided for still ought to be the responsibility of the biological parents. Adoptive parents assume moral responsibility because of their commitment and their explicit intention to the child.

For this thesis, a parent's moral responsibility is to be understood as accountability for a child's safety and development. Parental accountability consists in the potential blame or praise for their command or rule over their child's on-going development.

1.3.2(b) Parental Responsibility and Surrogate Decision-Making

Aristotle refers to a biological kinship that he assumes is shared by all parents and their children. Locke, on the other hand, explicitly establishes that one does not become a parent simply by virtue of biological relation. According to his view, one must earn the title of parent through one's actions. A parent is the person who cares for, teaches, and guides her child into maturity. This idea captures the notion that a parent is one from whom a child learns about her biological, ethical, and political identity.

Children develop into autonomous beings – beings that are able to act on their own behalf – because of the actions and guidance of certain adult individuals, specifically, those of their parents. These individuals, who take on the role of primary guide, counselor, and care provider, are the individuals who also serve as the primary influence on children's development.[50]

The idea that the title of "parent" is earned is important, particularly in today's society, because we can no longer assume biological kinship and because children are less likely to be orphaned at a very young age. Adoption, in vitro fertilization, and other advances in reproductive technology allow for individuals other than the biological mother or father to assume the role of parent. Moreover, changing social roles for women have expanded the number and nature of possible caregivers involved in a child's development. In light of this, parents' assignment to guide children into maturity is a particularly interesting one. Often there are adults who spend more time with a child or who know a child better in a specific capacity than a parent. An example of the former would be a babysitter who cares for the child while her mother and father are absent, either at work or for another reason. An example of the latter would be in a medical context where a child's pediatrician is often more knowledgeable than a parent about the status of a child's overall health. I believe that the key difference between a parent, a babysitter, and a pediatrician is ultimate responsibility. A babysitter cares for a child temporarily, in the absence of the child's primary caregivers. A pediatrician cares for a child's health ailments and guides parents in the child's overall, on-going health care, however a parent fulfills all of her child's general and specific needs until the child is sufficiently able to provide for herself. Examples of those needs are food, shelter, education, emotional support, and ensuring general safety.

Parents also invest a great deal of themselves in their children. Parents invest their time, effort, money, and emotions in their child's biological, ethical, and political development. Such an investment is necessary because children learn predominantly from their parents about the ways of the world and about their places in the world. It is through parents' actions with respect to their children that children learn how to treat others. Although a babysitter may influence a child in some sense, the babysitter's access to the child is as a surrogate. The babysitter is hired as an agent of the parents, by the parents, to ensure the child's safety while the parents are away. A pediatrician may also influence a child in some sense. However, the physician's access to the child is also as surrogate, limited and temporary. No other adult is involved in a child's life in the same all-encompassing sense as a child's parent(s). By this view, a child's parents must invest more of themselves, more consistently, and more diversely than any other adults involved in the child's care giving.

Another way to recognize the investment that parents make in their children is by recognizing the risk incurred by parents when something with respect to their child goes awry. Blame and praise for decisions made about their children are part and parcel of parental responsibility. A child's parents are accountable for hiring capable babysitters. If something goes awry concerning that babysitter, the child's parents are still ultimately accountable. Blame for ill hiring often includes suspicion of a parent's intention and ability to be a good parent. A parent's sense of responsibility for her child may be questioned. In this sense, parental responsibility carries personal risk. Parents open their decisions and actions to criticism and suspicion.

The investment parents make in their children and the degree of risk incurred in such an investment is greater than that taken on by secondary caregivers. This difference, accompanied by the many daily activities performed by parents, earns parents the position of surrogate decision-makers.

1.4 LEGAL EXAMPLE OF ENTRENCHMENT

The traditional legal positions regarding children and parents reflect the aforementioned traditional philosophical positions. The legal entrenchment of the philosophical position is most apparent in the laws governing proxy consent, becoming even more obvious upon analysis of the "best interests of the child" standard, which serves as an instructional complement to the laws of proxy.

According to the traditional philosophical position, children are not yet fully rational beings. Regardless of their status as rational beings, children are not void of needs and interests. Because children are not autonomous beings it is necessary for decisions regarding their needs and interests to be made on their behalf. The legal term for this special consideration is "proxy consent."[51] Proxy consent describes a general circumstance in which consent is not provided by the patient, but is instead provided by a surrogate. Here I will concentrate on the child patient.

1.4.1 Proxy Consent for Children

A patient's decision with respect to her own care is acceptable only if certain criteria are satisfied. Along with fulfillment of the criteria for autonomy explained previously, the patient's age is an important legal consideration. As we have already learned, the traditional philosophical position claims that age is an indicator of experience, and subsequently, of rationality. Although philosophically there is no established age over which one is considered an adult, there is such an age legally. Canada's legislation establishing age of consent for medical treatment regarding care varies from province to province. At the lowest end of the continuum is the province of Quebec where all children fourteen years of age and over can consent to care and treatment.[52] New Brunswick,[53] British Columbia,[54] and Ontario[55] have established the age of sixteen as the age for consent. At the highest end of the continuum are

Saskatchewan[56] and Prince Edward Island.[57] According to their legislation, the age of consent is set at eighteen.

With the exception of Saskatchewan and Prince Edward Island, all legislation regarding age of consent contains a disclaimer allowing for exceptions to the rule.[58] It is evident that consent from people under the age of 14 has also been admissible. In recent cases, the Supreme Court of Canada has even recognized the claims of children as young as twelve years of age to be autonomous.

Despite the disclaimers allowing exceptions, the needs and interests of children aged 12 and younger always require proxy representation. No federal or provincial court has yet recognized the decision of a child below the age of twelve as autonomous. In accordance with the ideas of Aristotle, Locke, and Rawls, proxy consenters are delegated the dual role of mouthpiece and role model.[59] Using their own deliberative faculties and experience of life, the proxies' role is to ensure that the child's needs and interests are represented in the treatment decision.

1.4.2 The "Best Interests of the Child" Standard

Legislators often complement new laws with instructional standards. These standards aid both the lawmakers and those to whom the laws apply to correctly employ and adhere to the law. The "best interests of the child" standard serves this purpose for the Common law. More specifically, the standard is intended to explicate what is meant by "interests" so as to guide proxy consenters in weighing the pros and cons of solution possibilities.[60]

As there is no formal definition of the term "interests," the concept of "best interests" is explained though individual case decisions. A child's best interests can be summarized as those aspects that maximize the child's physical and emotional health, moral structure, and status as a future citizen. For his reasoning in the case D.P. v. C.S., a case concerning child custody, Supreme Court of Canada's Justice Sopinka employs the definition of Quebec Supreme Court Justice Beetz, who explains that a human being's "interests" are equated with her physical welfare, emotional, intellectual, and finally, moral, religious and spiritual welfare.[61] Justice Beetz's definition is commonly referred to as a source for understanding the standard, and therefore, I will employ his explanation for the context of this thesis.[62]

1.4.3 The Legal Instruction to "Safeguard" the Interests of Children

Provincial legislation and related case law ensure that children's interests must be "safeguarded."[63] Proxy consenters must ensure the defense and promotion of the child's individual interests. According to legal literature, the instruction to safeguard is to be understood in a broad sense.[64]

Children are destined to become fully developed human beings, and stable and responsible citizens. Presumably, children will survive their parents. The survival of children does not just include the protection or security of children's interests but of society's as well. In cases where proxy consent is necessary, the child's interests with respect to the decision to be made must take precedence over those of the consenters' interests.[65] Even the laws regarding proxy consent specify that decisions be made in accordance with the way the patient would wish to be treated.[66] Decisions must not be in accordance with how the decision-makers reason they themselves would want to be treated or how other people believe the patient ought to be treated.[67] The interests of the child must be the paramount consideration when weighing treatment possibilities. The interests of the proxy consenters with respect to the decision to be made ought to be irrelevant. In this sense, “safeguarding” is to be understood as the protection of children’s interests by placing those interests in the forefront of the considerations.

CHAPTER II

CRITIQUE OF THE TRADITIONAL PHILOSOPHICAL POSITION

2.1 THE "ASSUMPTIONS ABOUT EXPERIENCE" PROBLEM

2.1.1 Age = In/Experience

The traditional philosophical position emphasizes that what children know about life is quantitatively different from what adults know. Since children have lived fewer years than adults, they have less general experience on which to reflect than adults have. This position implies that sufficient experience is quantitatively proportionate to age, and subsequently, that rationality is dependent on sufficient experience. In other words, because children are young in their years, they are also insufficiently experienced and thus, are not rational.

The likelihood of a person having more varied experiences as she gets older is high. The more time one has, the more time there is to invite and go through a variety of different experiences. It is not, however, necessarily true that someone who is older has experienced more in a specific domain or acquired more domain-specific knowledge, than someone who is young.

Domain-specific knowledge depends on a person's direct experiences in a specific area. For example, the fact that a hammer is long and thin and contains a head on top describes basic visual knowledge about hammers. That a hammer can be picked up at one and used to bang a nail with the other end, describes basic knowledge having to do with the function of hammers. However, because of her direct experience using hammers, a carpenter learns that there are some hammers appropriate for driving nails and others appropriate for finishing copper. A person's knowledge of the specific domain expands with respect to that domain as the person becomes more familiar with its specifics via direct interaction or experience with those specifics.

In contrast, domain-general knowledge is called upon across many different domains. One gains general knowledge via more indirect means. For example, an engineer selling a device may know everything about how the device works and why the device works, but without general knowledge about how to relate to customers it is unlikely that the engineer will succeed in the sale.

While some people gain domain-specific knowledge as adults, others acquire domain-specific knowledge during childhood. It is logical to assume that the more varied one's experiences are, the greater the variety of domains from which one can draw and reflect upon. The more opportunities upon which one has to reflect and the greater the variety of domains from which one can draw, the more rationally one can approach decisions in general. This assumed correlation is not unsound. It is, however, unsound to assume that because of their age, young people do not have sufficient domain-specific experience to competently reason through decisions related to the specific domains. Based on this reasoning, the traditional correlation between age and experience is complicated.

Aristotle, Locke, and Rawls claim that children do not grow to maturity without guidance and education from their parents. If a child has not been properly guided or educated, then the child will not develop and mature properly. Though a person may have reached an age commonly associated with maturity, that person might still be ruled by emotion and lack rationality. It is more fair to claim that one is only as rational as one has learned or been taught to be, an association that is only indirectly related to age. This is not to say that age, experience, and rationality are unrelated, but, more plausibly, that the way one comes to develop the ability to approach issues rationally is related to one's role models and to the nature of one's experiences.

Rawls explains that in the first stage of moral development children associate their behaviour with the commands of their parents. It is not until the second stage, the morality of association, that children begin to recognize themselves in relation to events and to other people. Until this stage, children measure or assess events and people through their authority (held primarily by their parents, but also held by others).

Research in child psychology has found that children around the age of five begin to consciously take an interest in the community to which they belong. This is because once the child begins attending school, she begins to recognize herself as a social being.[68] At this age, a child's language skills also begin to change, as they must accommodate the child's changing status. Before the age of 6, children do not reflect on language as a communication tool and on the self as a user of language. However, by the age of 6, children come to understand that words are often different from concepts and that some words sound the same as others but do not share the same meaning.[69] At this age, children also begin to understand and appreciate more complex uses of language such as humour and metaphor.[70] Those skills are important for understanding the intentions behind a person's words and to formulate appropriate responses.

Using their newly developed language skills, children begin to practice what is known as "needs oriented reasoning,"[71] which involves expression of concern for the needs of others. Prior to this stage, children are preoccupied with self-gain and cannot be expected to seek help for a playmate who is hurt or struggling.[72] However, over the course of the elementary school years, children are in a "stage of conscience."[73] This is the stage at which a child's sense of self changes from one that is solely motivated by parental command to one that is motivated by how her behaviours and decisions will affect the greater community.[74] The perspective from which children approach decisions and new experiences changes. While previously the child sought solely her parents' approval or disapproval, now the child seeks to ensure a specific result.[75] It is also at this stage that children begin to associate symptoms with a specific illness, to understand the progression of illness through stages and to comprehend the logical association between ailment and potential cure.[76]

Children in this age group also assert "information-seeking behaviours,"[77] focusing less on technical data (e.g. that her mother forbade her to have a cookie) and more on the impact that the data will have (e.g. behaving in a forbidden way may reap negative consequences). It is at this stage that a child begins to realize the degree to which the locus of control in a particular matter is internal and subject to her decision, or external and a matter of other external factors.[78] Empirical evidence shows that such skills are most substantially developed between the ages of seven and twelve and are well developed by the age of twelve.[79]

The remainder of this thesis will focus on children who are six years of age and older because of the way that children between the ages of 6 and 12 begin to see themselves as individuals and in relation to other people. Although development varies child to child and circumstance to circumstance, in general, children below the age of 6 have not fully entered this stage of consciousness, and therefore, do not yet approach experiences and data from a reflective perspective.

Based on the above considerations, children less than six years of age are unlikely to effectively comprehend the idea of options and are less able to weigh benefits of one option against those of another. By restricting this discussion to children who have graduated to the second Rawlsian stage of moral development, the morality of association, it is possible to confidently defend future assertions.

2.1.2 Domain-General Experience, Domain-Specific Experience, and Moral Development

Having experience in a specific domain can overcome limitations imposed by a lack of general life experience. This further complicates the traditionally assumed relationship between age, experience, and rationality. Contrary to that assumption, it is still possible to gain enough knowledge in a specific area so that, despite age, one can make autonomous decisions about issues related to that specific area.

Ample evidence exists showing that when the task is specific to familiar domain children can reason logically, integrate general knowledge, and make generalizations. In an experiment done by psychologist Michelene Chi, six children, ages 8 through 12, were solicited from a local chess competition.[80] Six adult academics were also solicited. Though all of the adult participants knew how to play chess none of them had ever played competitively. A series of chess positions were presented twice, each time over the course of ten seconds. The participants were asked to reproduce the series with all pieces, colours, and locations exactly as they were in the original demonstration. The trial continued until each participant could reproduce the entire series perfectly. While 59% of the children were able to reproduce the series on the first try, only 44% of the adults were able to achieve the same result.[81] These results are explainable by the fact that the children had more experience playing chess and thus had more knowledge of the patterns and strategies. Based on the these results Chi concludes that the amount of knowledge a person possesses about a specific area can determine to a large extent how well the person can perform with respect to that domain.[82]

In a similar experiment, two groups of beginner and advanced tennis players were evaluated for their performance and knowledge of tennis.[83] The beginner group consisted of adult players and the advanced group consisted of children ages 8 through 13. The advanced players focused on higher-level concepts and recognized more connections among concepts than the beginners.[84] This differential knowledge base affected actual tennis performance.[85] According to the administrators of the experiment, the beginners attempted to solve tennis-related problems using general and not domain-specific knowledge.[86] Just as knowledge of chess strategies affected the success of the participants in the Chi experiment, knowledge of tennis also affected how the other participants made decisions during a match and how well they executed their sport skill.

These empirical observations show that adults may have very "novice-like" reasoning in domains where their own experiences are limited. A person's inability to maturely understand and act upon certain information may be due less to structural inabilities related to age and more to the nature of specific knowledge deficits. The degree to which a child can behave rationally may have to do with individual experience within the relevant domain.

In this sense, it is unsound to claim that children are entirely incapable of behaving autonomously. The quantity and quality of a specific experience is a factor in the quality of a person's knowledge within that particular domain. Children may not have a general pool of knowledge because they have fewer general experiences, and therefore, may not be able to participate rationally in general moral decisions, but they may be able to participate rationally in specific decisions depending on the quantity and quality of their specific experiences within that domain.

CHAPTER III

WHAT THE MORAL POSITION OUGHT TO BE

In light of the previously discussed implications and concerns, revisions ought to be made to the traditional philosophical position with respect to children and parents. The revised position ought to take into account that the degree to which a child can behave autonomously may also have to do with individual experience within a specific domain and not solely based on general experiences in a variety of domains as traditionally thought. Appropriate changes not based on traditional assumptions about age, experience and autonomy ought to be accommodated. The revised position also ought to reflect the actual moral behaviour of children.

3.1 CHILDREN CAN PARTICIPATE IN THE MAKING OF SOME MAJOR DECISIONS

In explaining the "Assumptions About Experience" problem, I stressed that the quality of experiences in a specific domain strengthens one's ability to make rational decisions within that domain. It is for this reason that the traditional philosophical position regarding children ought to be altered. In the upcoming section I will show that children do make choices when given the opportunity and I will assess whether some of these decisions can be considered autonomous (i.e. made freely and rationally). I will also argue that all children, though some to a greater degree than others, ought to participate in the making of decisions that pertain to their own care.

3.1.1 Children Do Make Choices

Given the opportunity, children do make decisions. Evidence of this is substantially empirical; the bulk of my argument is based on observations of how children actually behave under certain circumstances, rather than on theoretical predictions of children's behaviour.

In Canada, most children begin kindergarten when they are approximately 5 years old. The transition from home-life to school-life brings with it new responsibilities and new opportunities. Often, parents or teachers warn children that they should "make good choices." Indeed, children may be expected to choose their own clothing for the day or to choose appropriate and kind behaviour towards siblings, parents, teachers, and friends. Children must also make choices regarding their schoolwork. For example, children must choose to bring their workbooks home or prepare and study for tests. As children grow older, they are expected to make choices about different kinds of social behaviour such as drug or alcohol use and sexual activity.

When presented with options, children do weigh potential pros and cons, assess potential reactions and effects, and proceed from there.[87] The capacity to make decisions is exercised every time a child wakes up in the morning and decides what food she should eat for breakfast (or whether to eat what is put in front of her). Her decision-making skills are exercised again once she gets onto the school bus and takes on the role of a social being.

That children do make choices does not necessarily mean that children will always make the choice that an adult would make under the same circumstances. According to the traditional philosophical position, children are not fully rational beings. They are ruled by emotion, desire, and passion rather than by reason and logic. In this sense, children are more likely than mature adults to base their decisions on how they predict the action, or the result of their action will, make them feel. Moreover, children are more inclined to base their decisions on how they predict their parents and contemporaries will react to their decision and its results.

Because of these considerations, it is generally true that children do not make autonomous choices. Recall the conditions of autonomous behaviour. First, in order for an agent to be considered autonomous, her decisions must not be based on negative influence. Second, she must be able to exercise rational self-control.

In general, children's decisions do not satisfy either of these considerations. A lack of domain-general knowledge forces children to rely directly upon guidance and feedback from parents. Due to their underdeveloped rationality, it cannot be said that children rationally control their choices and behaviour. Furthermore, children cannot accept responsibility for their choices. One of the main responsibilities of parents is to influence and guide the behaviours of children until they gain enough knowledge and experience to make independent decisions about their behaviour. The behaviour of children is influenced to such a degree by parental example and constraint that responsibility for that behaviour does not fall on the child. The child's decisions are not free of inappropriate influence. The encouragement or reprimand of others in response to the behaviour communicates the rightness or wrongness of the action to the child and determines whether or not the behaviour will continue.

Based on the evidence above, the traditional assumption that children cannot make autonomous choices seems accurate. I agree that, generally speaking, children <u>cannot</u> make autonomous choices. Children lack the general experiences and general knowledge to make those decisions autonomously. However, it is possible that, despite their lack of general knowledge and ability, children can still make specific decisions competently.

3.1.1(a) Domain-Specific Decisions

The case in which a child may be able to make an autonomous decision is one in which the child's decision is task or domain specific. As explained earlier, maturity is developed through experience and reflection. Ethical maturity is developed through the guidance of reason and is cultivated through the repeated exercise of restraint and of virtuous conduct. Such exercise is only possible if opportunities that demand action present themselves. Because children are young in years, and subsequently lack experience in general, children usually have not been presented with a plethora of opportunities that demand action. On the other hand, domain-specific experiences act as catalysts, pushing specific capacities to develop faster than general capacities. In turn, children can act more freely and more rationally with respect to those specific capacities.

It is necessary to employ a specific example in order to further assess the effect of domain-specific experiences in the context of children. I have chosen to concentrate specifically on chronic and terminal illness for a number of reasons. First, by definition, chronic illness is ongoing. Over time the patient is presented with constant opportunities to explore and develop a better understanding of the illness, as well as its direct effects on her. The patient is also presented with opportunities to witness her parents' decision-making capacities. Terminal illnesses are also generally not short-term experiences. The illnesses, and sometimes treatment of the illnesses, carry long-term repercussions. Second, the decisions made with respect to treatment of chronic and/or terminal illnesses are often life-changing decisions. Such decisions overwhelm all general aspects of the child-patient's life as well as the lives of the other members of patient's family. Under these circumstances the best interests of the child must be established, re-established, assessed, and re-assessed, depending on new prognoses. The attitude taken towards treatment options will affect the way the child approaches other options in the future.

3.1.1(b) The Chronically and/or Terminally Ill Child

Myra Bluebond-Langer studied 50 children diagnosed with acute lymphocytic leukemia.[88] Ages of participants ranged from three to nine years old. At the time of her study, in the 1970s, the prognosis for such patients was quite poor. Five years later, when Bluebond-Langer finished writing her study, none of the children were still living.

What emerged from her study is that although children do go through identifiable stages[A] in coming to understand and deal with the onset of their own deaths, those stages are not correlated with age, but instead are correlated with experience.[89] Bluebond-Langner explains the

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[A] The stages Bluebond-Langner identified are: **Stage 1:** The children learn that "it" (not all children knew the name of the disease) was a serious illness. At this time they also accumulate information about the names of the drugs and their side effects. **Stage 2:** By the time the children reach this stage they know which drugs are used when, how, and with what consequences. **Stage 3:** An understanding of the special procedures needed to administer drugs and additional treatments that might be required as a result of the drugs' side effects marks this stage. Each procedure, each treatment, is recognized as a unique event. **Stage 4:** The children are now able to put treatments, procedures, and symptoms into a larger perspective. They began to understand the disease as a series of relapses and remissions, and that one can get sick over and over again in the same way, and that medications do not always last as long as they were supposed to. **Stage 5:** At this stage, the children realized that there were a finite number of drugs and that when these drugs were no longer effective, death became imminent.

importance of a child's experiences this way: "The place of experience in the socialization process illuminates why a child could remain at a given stage [of understanding and dealing with the onset of their own death] without passing to the next for what seemed to be an unusual length of time."[90] She explains that one child, "Tom," remained at stage 4 for a year, whereas another child, "Jeffrey," remained at stage 4 for only one week. Passage to stage 5 depended only on the news of another child's death. No children died after Tom reached the 4th stage and therefore he could not pass to stage 5. When a child did finally die that year, all the children in stage 4, regardless of how long they had been there, passed to stage 5.

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.[91] Some three and four year olds of average intelligence knew more about their prognosis than some very intelligent nine year olds, who were still in their first remission, had fewer clinic visits, and hence had less experience.[92] In other words, the children with sufficient experience in this specific domain, namely terminal illness, developed specific capacities necessary for participating in that domain. A child with a sufficient understanding of illness and death is equipped to understand the seriousness of life-threatening illness or injury and to appreciate what success and failure in treatment amount to. With these tools, such a child has the potential to make a rational contribution to choosing the best course of treatment.

In general, children with terminal cancer are interviewed and questioned over and over again about their symptoms, side effects, and degree of comfort. Children with chronic and terminal illnesses must assess internal changes with respect to symptoms or environment, and judge when it is important to communicate these changes to their caregivers. As a result, the communication and evaluation skills of these children advance with their illness.[93]

Because of this advancement, chronically and terminally ill children may make autonomous choices within the domain of their illness. These children might still be novices about the world in general, but they have subjective expertise in their illness' interaction with their body. In the following paragraphs, I will show that chronically and/or terminally ill children <u>can</u> make autonomous choices with respect to the treatment of their illness. Such an assessment is based on the conditions set forth in Section 1.3.1(a).

The first condition of autonomy is that the agent must make decisions free of inappropriate influence. Decisions with respect to one's own care, typically ought not be based on or be the result of the wants and interests of other people. The chronically and terminally ill child recognizes that only she is the patient and that the main goal of her treatment is to heal her of the ailment.[94] She knows this because she is the only one who can answer her parents' and health care workers' questions concerning her symptoms and treatment side effects subjectively. Health care workers obtain objective measurements of the patient's discomfort by using diagnostic technology (x-rays, MRIs, etc.). Since the patient is the one enduring the illness, she is the expert – the one with the answers – about how the symptoms and side effects are really making her feel. Using the information provided by the patient, the health care physicians assess treatment options and prognosis.

The child comes to realize the value of her contribution through comments and dialogues shared with health care workers, parents, and other patients.[95] Constant coaxing, prompting, and assuring of the child by her parents or health care workers also conveys the message that new results may be uncovered due a particular comment or observation voiced. Any variation in the patient's symptoms can make a difference to treatment and recovery. If the child does not report precisely and truthfully, then essential information and, possibly, treatment options will be lost.

It is evident based on empirical observations that these children realize the importance of their contributions to diagnosis and prognosis. In light of this, children do report their symptoms. However, this behaviour comes as a result of parental pressure and constant prompting. Their behaviour is ultimately free from inappropriate influences, but the drive behind that action is not ultimately self-motivated. Providing that the level of parental pressure and prompting is not recognized as inappropriate, the child can be recognized as acting freely.

The second condition for autonomy is that the agent must have rational control of her decisions and actions. The child must not base her decisions solely emotions but instead must also reason through her options using judgment and reflection. With experience, children dealing with serious illness learn the difference between short-term relief and long-term remission.[96] Short-term relief allows the child to feel better temporarily, however the illness still lingers. The latter option presents the child with lasting and continuous relief. After experiencing short-term relief over and over again, the child realizes that, with such treatment, the symptoms of illness eventually return.[97] The prospect of long-term remission as emphasized by health care workers and by the child's parents becomes the reasonable goal, even in the eyes of the patient.[B] The child behaves rationally, basing decisions on reasonable goals and reasonable considerations. Short-term concessions are made in order to achieve long-term benefits.

The decisions made by all chronically and terminally ill children about their own care cannot be deemed entirely autonomous. However, the degree to which their decisions are autonomous ought not be ignored. The extent of such a child's participation in the process of making decisions about her own care ought to accommodate both the degree of autonomy she has developed in regards to her illness and the degree of general autonomy she has yet to develop. In the following subsection, I will argue that, in fact, this claim about participation in the making of decisions about one's care ought to be taken as true in regards to all children.

[B] I realize that this analysis is only true up to a certain point in terminal illness. Once the illness has passed a certain stage (stage 4 according to Bluebond-Langner's stages), remission is no longer a reasonable goal. Temporary relief from symptoms and treatment side effects may indeed become the reasonable option, while continuing to hope for remission becomes the emotion-based option. My aim with this example was simply to illustrate that children do not always opt for the emotion-motivated route, but, instead, can recognize the reasonable route.

3.2 CHILDREN SHOULD PARTICIPATE IN THE MAKING OF DECISIONS THAT PERTAIN TO THEIR CARE

The primary consideration as to why all children ought to participate in the decision-making process is that children are not born with autonomy. The capacity to make choices independent of others' influence is, paradoxically, one that is developed due to the influence of others. According to the traditional philosophical position regarding children and their parents, it is the role of parents to care for and guide their children to maturity. This position holds that the main goal of parenting is to educate children through virtuous example of how to behave autonomously.

Children develop mature insights in stages. First, children base decisions on the example of their parents, then their contemporaries, and only then do they begin to base their decisions on reason and principle. In general, all children develop through these stages and are more autonomous in some ways but less autonomous in others. As experiences become quantitatively more frequent and her ability to reflect on those experiences becomes qualitatively better, the child's ability to reason independently develops. For example, as a child meets more people, expands her peer group, and develops more intimate relationships with specific peers, the child will also develop an ability to reason through actions with regard to other people.

In light of this, all children ought to participate in the making of decisions about their own care. As children experience themselves more (in interacting with their friends, their work, their own care), their sense of self becomes better defined (along with that, a sense of needs and interests develops), and their ability to make rational decisions on their own behalf will develop.

As I concluded in the previous sub-section, the degree of autonomy that a child has developed as well as the degree to which the child must still develop ought not be ignored. The extent of a child's participation in the making of decisions ought to complement the child's development. For this reason, the extent of the child's participation must not only be assessed on the basis of illness appropriateness and experience appropriateness, but also must be appropriate to the child's ability to communicate and understand ideas and concepts.

3.3 EXTENT OF PARTICIPATION

3.3.1 Communication Appropriate

Children ought to participate in the decision-making process to the extent that their ability to understand the information provided to them, and their ability to communicate responses to that information, permits. A child's ability to understand ideas and concepts, and communicate responses depends largely on the extent of their language skills.[98] Participation is limited if the child cannot understand the words used by others and cannot recall or add new words and meanings to her own vocabulary. Participation is also limited by the extent to which a child chooses words that accurately communicate whatever it is that she is attempting to describe or explain.

As explained earlier, evidence from psychological research illustrates that children only become proficient listeners and speakers once they begin school. Membership in a social group demands efficient use of and understanding of words. In order to be considered a social being, a child must be able to communicate with other social beings (e.g. their classmates). If a child has not yet developed the ability to communicate her wishes, or is unable to respond appropriately to questions about her illness, then her participation is not helpful to the decision-making process. Without the understanding that words are a tool for communication, and that listening closely and choosing one's words carefully and accurately is important part of that tool, a person's effectiveness as a communicator is reduced.

3.3.2 Illness Appropriate

The extent of the child's participation also ought to be appropriate to the nature of the effects of the illness on the patient. The same is true with respect to the extent of an adult's participation in decisions that pertain to her own care.[99] A patient who is undergoing chemotherapy may be so ill from the side effects that her decision-making capacities are diminished. The patient may also be so physically weak that she does not have the energy and focus required to properly exercise the necessary capacities. When a child is in this situation, it is the parents' responsibility as the child's role models and primary care givers to do the best they can to replicate the decisions that would be made if their child could contribute to the decision-making process.[100]

3.3.3 Experience Appropriate

Novices become experts via participation. In other words, all experts were at one time novices. Through hands-on experience with a skill or trade, the novice begins to develop and fine-tune her abilities. Once those abilities are developed and fine-tuned to a certain degree, the novice "graduates" to expert. Without recognizing the key role that participation plays in the development of expertise, one cannot expect to earn expert status.

The same is true with respect to children and their development. The traditional philosophical position is that children develop maturity through imitation. It is through the imitation of their parents' behaviours that children gain mature perspectives. In the context of decision-making, imitation, action, and practice take on the same type of role. When the child-patient participates in the decision-making process her skills in that area can be molded so that they advance and mature in a productive and effective way.[101]

A child who is newly diagnosed with her illness is still a novice because she has yet to experience and participate in the specific domain of her ailment. Such a child's participation ought to be limited to observing adults making decisions. As the traditional philosophers claim, children learn primarily by imitating the actions of their role models and evaluating the subsequent repercussions. Accordingly, the novice child who continuously observes her parents or other adults deliberate over decisions will begin to imitate their behaviours, techniques, and considerations, and will integrate them into her own personal decision-making process.

Once a child is an expert in a specific domain, she has gained sufficient experience in that domain to be able to participate in the decision-making process. As argued in Section 3.1.1(b), decisions made by chronically and terminally ill children with respect to their own care do not fulfill the conditions for autonomy. Their decisions cannot be recognized as both free and entirely based on reason as opposed to emotion. This is due to parents' ultimate influence on the child's behaviours and ultimate responsibility for ensuring their children's overall care and development, and due to children's general inability to sufficiently link domain-specific decisions with general implications.

Not all chronically and terminally ill children can decide for themselves nor can they be permitted to fully participate in the making of decisions that pertain to their own care. However, the extent to which they can make decisions competently must be nurtured and developed further. Consequently, I propose that chronically and/or terminally ill children, who are above the age of six but have not yet established expert status, be considered co-participants in the decision-making process.

As a co-participant, the child contributes to the deliberations and final decision, but does not participate to the same extent as her parents. As her role models, safe-keepers, and caregivers, the child's parents maintain ultimate accountability, and hence, they must ensure that no error of assessment is made with respect to the child's best interests. Essentially, the parents will be held accountable for the final decision made and for the repercussions of that decision. Still, the child's maturity is acknowledged and the skills that still need to be developed are exercised.

In the following section, I will elaborate more fully on the extent of both the novice child's, apprentice child's, and expert child's participation. The section will include recommendations for application of the revised moral position and solutions for potential problems with this approach will be provided.

CHAPTER IV

APPLICATION - WHAT OUGHT TO BE DONE

4.1 CURRENT APPROACHES

Before putting forth my proposal for application of the modified moral position I will outline three approaches to medical decision-making involving children, that are currently employed or being proposed for employment in North American health care facilities. Implementation of these models will vary from facility to facility, but the basic aims and methods remain common.

4.1.1 Peripheral Participation

I call the first model for participation of children in health care decision-making "peripheral participation."[C] Here the child is permitted to begin asserting her autonomy in making decisions peripheral to her specific treatment program. For example, although the child is not permitted to participate in the decision about whether or not to receive inoculations, she is permitted to choose the arm in which to receive the inoculation. Similarly, the child is not permitted to decide whether or not to receive chemotherapy, but she is allowed to choose which days she enters the hospital for the treatments. The child might also be permitted to choose the hat or wig that she wears once the treatments cause her hair to fall out.

4.1.2 Assent and Dissent

Whereas in the previous model the child is permitted to make only peripheral decisions, this model grants the child the power to agree to a certain treatment or to protest against the treatment. The process of assent involves the communication of all relevant information regarding treatment options. Dissent, on the other hand, involves a situation where upon considering all the relevant information the child objects to the treatment decision. According to Broome and Stieglitz, dissent is an "interactive process between a child and a health care worker involving disclosure, discussion, and a limited understanding of a proposed

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[C] In his article, "Circumscribed Autonomy," Hugh LaFolette discusses a version of this approach. He refers to it as "Administered Autonomy," 149.

treatment, wherein the child freely expresses an objection to participate [sic]."[102]

In either a case of assent or dissent, the child's decision is requested only after her parents have made their decision.[103] Whereas with peripheral participation, the child is permitted to decide the arm in which to receive the inoculation, in this model the child has to assent (or dissent) to the fundamental decision of whether or not to receive the inoculation.

Valid assent or dissent is based on three criteria: the child's basic understanding of the treatment proposal, assessment of the child's understanding of this information, and solicitation of the patient's willingness to accept the treatment.[104] The American Code of Federal Regulation specifies that assent is the child's clear, affirmative agreement to participate in treatment and *not* simply a failure to object.[105]

Because assenting necessitates that the child agrees to the decisions made by someone else, the child does not make the actual decision for herself by herself. When the child dissents, parents and health care workers attempt to convert the opposition into agreement.[106] This is because the model takes into consideration the child's legal incompetence as its base and works to accommodate it. Proxy power remains in the hands of the parents, but the child is given the opportunity to understand and support the proxy's decision.

4.1.3 "Constrained Parental Authority"

Friedman Ross presents another approach for involving children in health care decisions.[107] This model permits broad parental discretion. Friedman Ross presupposes that families are intimate groups whose members have both personal as well as shared goals.[108] By "intimate group" she means a psychologically bonded group whose relationship persists over an extended period of time and whose members share in each other's goals.[109] She advocates the maintenance of the basic needs of the family unit and the individual family members. Since individual needs and interests do not exist in a vacuum, they should be evaluated alongside the needs and interests of other intimates.

Maintaining that no one set of priorities is better than another, this approach allows for the emphasis that families place on different social goods. The decision made is considered to be acceptable providing that the child-patient is not neglected in any primary interests such as education, health, safety or the availability of an appropriate peer group and providing that neither the children's nor the parents' primary interests are compromised.

4.2 CRITIQUE OF CURRENT APPROACHES

4.2.1 Suitability as a "Model"

All three approaches discussed above are depicted in the literature as "models." A model is a potential clinical manifestation of the moral considerations relevant to the situation at hand and the laws that parallel those structures. It takes the situational goal into account and presents an approach to achieving that goal. Therefore, the aim of a model is to present people with a conceptual tactic for dealing with the moral, legal, and in the case of medicine, clinical aspects of the given situation. In the context of medical decision-making for children, as discussed in this thesis, a model acts as a conceptual tool, the application of which would enforce theoretical principles such as respect for and protection of the child-patient's best interests as much as possible, while also fulfilling the laws depicting valid proxy consent.

Both "peripheral participation" and "assent and dissent" reconcile the moral and legal aspects relevant to decision-making for children and suggest clinical means through which parents and health care workers can maximize the prevalence of those aspects. In the case of "peripheral participation" parents maintain their role as sole consenters to treatment decisions that pertain to the child. At a minimum, the interests of the child are respected peripherally because the child is permitted involvement and control over the minor issues. In the case of "assent and dissent" the child is permitted further involvement in even the most major decisions. Although parents ultimately provide consent, the child's decision-making skills are exercised and the child's wishes are shared and discussed to a certain extent.

The third approach outlined above, "constrained parental authority," seeks to accommodate the difficulty parents often face in accommodating solely the interests of one of their children and relinquishing personal interests. The tenet that the interests of the family unit ought to be considered as a major consideration in the decision-making process, is not a tool for clinical application, but sets forth a behavioural expectation as does the best interests of the child standard. The aim of a standard is to establish a level of behaviour that people ought to strive for. On their own, standards like the best interests of the child standard do not contain sufficient content to determine how we achieve the level or type of behaviour they advocate in specific contexts. These standards are meant to apply to a broad range of cases, all those that involve decision-making for children. This includes custodial, educational, religious, medical, and many other types of decisions that must be made on children's behalves. Friedman Ross's approach does not provide parents of chronically or terminally ill children with a means of incorporating the interests of the family unit into the decision-making process. In this sense, "constrained parental authority" cannot be deemed a model.

4.3 APPLICATION OF PROPOSED MORAL POSITION

An effective model for involving chronically or terminally ill children below the age of consent in the process of medical decision-making ought to satisfy the theoretical principles identified in section 3.3. The model must place the child-patient's interests first and foremost in the criteria upon which the decision is to be based. The child's overall development ought to be satisfied, promoted, and protected by the proxy consenters. Furthermore, the child's ability to make autonomous choices ought to be nurtured and developed further.

4.3.1 Integrating the Novice Child

"Peripheral participation" is the weakest form of an approach for decision-making that I advocate. Because children are permitted to employ some of their decision-making skills, I believe that the goal of this model accommodates the parents as well as the novice child. By limiting the novice child's participation, conflict is avoided. The parents have already made the important, life-affecting decision and the child is left with the experience of having made peripheral decisions. In conjunction with the illness experience, chronically or terminally ill children over the age of six have already developed the cognitive ability to assess certain issues in relation to other relevant information presented to them in an age-appropriate manner. Children of this age also have developed the language skills so that they can communicate responses to such issues. Choosing the arm in which you will receive an inoculation requires a simple deliberation, much simpler than the capability of a child beyond the age of six who has experienced chronic or terminal illness.

I support the peripheral participation methodology in regards to the novice group because children who have not been chronically ill cannot be said to be experts about their symptoms and illness, and cannot be said to have already formed these capacities. Inviting children who are still inexperienced with their illness to make these sorts of peripheral decisions may encourage the development of their assessment skills and will potentially lead them to look differently at their experiences. This is beneficial, not only because it allows the child's skills to develop, but also because it allows parents the opportunity to work with their child as decision-maker. This will positively affect future situations where treatment decisions will be reviewed, assessed, and perhaps altered. The parents and health care workers will have seen the child make decisions, trivial or not, and may, in turn, feel more comfortable allowing the child more decision-making responsibilities. This is an appropriate way to integrate the novice child into different aspects of her health care program.

4.3.2 Moving Beyond Novicehood

There is a stage between novice and expert at which point the child can be considered something of an apprentice. This middle stage bridges the gap between novice and expert. Whereas a novice child has little to no experience with her illness, symptoms, or with the health care system, the apprentice child is one that is learning while experiencing. The apprentice child is coming to know her body, her changing aches and pains, and is becoming more familiar with the health care workers, health care environment, and terminology.

The "assent and dissent" approach is most appropriate for children in the apprentice stage. The opportunity to assent or dissent to a proactive procedure, such as surgically setting a thrice broken limb in order to synthetically strengthen and prevent it from breaking so easily, allows the apprentice child to draw on past experience, to employ developed skills as well as other still developing skills while gaining psychological benefits, such as higher self-esteem and a sense of dignity. The occasional employment of decision-making skills furthers the child's general ability to make decisions, and when the opportunity should arise, will strengthen her position as a co-participant in the deliberation process.

Allowing the apprentice child the power to assent or dissent to a treatment proposal requires that a certain amount of information be offered. In my explication of the "assent and dissent" approach I explained that the treatment decisions are made prior to the child's involvement. I propose that the apprentice child be considered a <u>co-participant</u> and be present during treatment deliberations, even though she will not be asked to assent until after deliberations have been resolved, and even in the decision involves discontinuing treatment. I recommend this not only because the essential information and explanations are presented in the early stages, but also because it permits the child to witness early interactions and dialogues shared between her parents and the health care worker(s) at the point of decision-making. This is important because personal experiences move the child from novice status to expert status. Skills will develop as the child witnesses other people exercising those skills.

However, I do not recommend that a novice or apprentice child be present during delivery of test results, diagnosis or prognosis. The first time that parents receive such information is a very emotional event. Such exposure would only be detrimental to the child's developing perspective on the pending situation and would likely affect her experience of the illness and of the decision-making process.

4.3.3 The Expert Child

The nature of questions, concerns, and comments asserted by the child-patient will help parents and health care workers determine when the child has become an "expert." As already recommended, it is only once parents are confident that their child has reached this stage of experience and ability that the child ought to be considered an expert about her body and her illness. In this light, the child ought to be expected to contribute more than assent or dissent to treatment decisions. She ought to be expected and encouraged to assert concerns, posit questions, demand clarification, and ultimately, make the final treatment decision. The child's hesitations also ought to be dealt with and taken into account. The contributions of the child ought to be addressed with the same seriousness as those of an expert adult-patient.

Once those involved are confident in the child's level of understanding about treatment options, side effects, and prognosis, decision deliberation begins. Due to the degree of guidance and influence of parents on the child, her decisions ought to be investigated for evidence that the final decision made is not the result of inappropriate influence or due to misunderstanding. Hesitation about inaccurate assessment of what the expert-child considers to be in her best interests might be lessened if the parents and the child (perhaps even the family unit) can establish the relevant non-medical considerations prior to treatment deliberations. Examples of such considerations would have to do with how much school the patient would have to miss, how much time the child would have to spend in the hospital and not at home, the distance between home and the treatment center, whether or not the child would be permitted visitors during treatment, or even the financial cost of the treatment plan. The considerations, although likely to be similar case-to-case, ought to emphasize the interests of the individual child and perhaps the family unit. Once those involved have helped the child establish a strategy upon which her decision will be based, concerns regarding focus are diminished.

The degree to which the child contributes to the treatment debate is the defining feature of expert status. The expert-child's view ought to be accepted as autonomous and ought to be accepted as the final decision over that asserted by her non-expert parents. Despite their commitment and desire, parents are unable to achieve the same expert-status with regard to their child's illness, as their child is able to achieve. Regardless of research done, conferencing with specialists and other health care workers, parents cannot have the same subjective insights into their child's sick body, as does the child. In such cases, parents can make suggestions and propose relevant considerations, however the expert-child maintains her status and holds a veto-right over all parental propositions.

4.4 CRITIQUE OF APPLICATION OF PROPOSED MORAL POSITION

This model is not without its difficulties. There will be those who argue that certain parts of the model, if not the model in its entirety, either fall short of or are contrary to the criteria for a model useful in integrating chronically and terminally ill children below the age of twelve into the medical decision-making process.

4.4.1 Strain on the Parent-Child Relationship

The main objections that I must deal with here are regarding the complexities of the parent-child relationship.

4.4.1(a) The Influence of Parents on Child-Patient's Preferences

The first claim to address is that children, whether novice or expert, are strongly influenced by their parents. A useful example to cite is the recent Saskatchewan case Dueck (Re).[110] The case centered on thirteen-year-old Tyrell Dueck who, diagnosed with osteogenic sarcoma in November of 1998, fought to refuse further conventional treatment and opt for alternative treatment. The courts found Tyrell to be a child in need of court protection because he claimed that his cancer had been cured by G-d and because he refused to complete his final round of chemotherapy.[111] Through a lawyer, Tyrell applied to have the protection order lifted and to have his wishes honoured. Instead, Justice Alison Rothery ordered Tyrell and his parents to undergo psychological evaluation.[112] Her apparent goal was to determine the degree to which Tyrell's decision was influenced by his parents' fundamentalist Christian beliefs.[113]

A key point of interest is that Tyrell's father insisted that he be present at all of Tyrell's medical examinations and consultations. Tyrell was never permitted to speak privately with his health care workers.[114] Such an insistence could be interpreted as parental protection of the child. Had Mr. Dueck not been deceiving Tyrell by supplying him with false information and false hopes (Tyrell's cancer had not been cured and was quickly spreading to other parts of his body), perhaps this insistence would not seem suspicious or unhealthy.

Justice Rothery concluded that Tyrell's decision had been unduly influenced by his parents, or at least, by his father.[115] She concluded that because the information upon which Tyrell was operating was incorrect, Tyrell had been given no real choice at all, but instead, had been misguided and misinformed.[116] In light of these conclusions, Justice

Rothery ruled that although Tyrell may have had the maturity to make his own decision, he was not able to do so at that time because he did not have accurate information.[117]

Tyrell's father's misguidance prevented Tyrell from moving beyond the status of apprentice. Though he had experienced his body with respect to his cancer for a long length of time and had been present at discussions with physicians and other health care workers, Tyrell was not permitted to meet with physicians on his own. All of the physicians' contributions and recommendations were filtered through Tyrell's parents. In these ways Tyrell's expertise in the context of his illness was overshadowed by his parents' focus on their religious beliefs. The Duecks hindered Tyrell's development from apprentice to expert by refocusing relevant considerations through a non-medical context (i.e. religion). Tyrell could not, therefore, effectively weigh considerations directly relevant to his physical healing. Influence to this degree and of this nature is not complementary to the autonomous decision-making that an expert is capable of.

This difficulty is a serious one for my approach. I am arguing that children who are in the apprentice stage should be co-participants in medical decisions about their own care. While present during treatment deliberations, the child-patient will inevitably pick up on parents' comments, concerns, and treatment preferences. I am relying upon the maturity of the parents and health care providers to guide the appropriate and inappropriate additions to the discussion. In no way am I encouraging parents to withhold comment. I am, however, counting on parents' ability to present questions and concerns in such a way that the child will not feel that her own position is being pressured one way or another. Such undue influence hold potentially expert children back at the apprentice stage (as is the case with Tyrell Dueck). A child cannot fully exercise her expert status if parental reaction encourages her to feel she ought not voice an opposing opinion or that she ought to make certain concessions with respect to her health care .

The suggestion made above is based on the assumption that all parents aim to protect their child's best interests in a fair and forthcoming way. Hospitals and social service programs already employ advocates, whose job it is to step in and ensure that the child's rights are honoured and protected. In cases such as Dueck, where the parent unduly influences his child's own position, these child advocates must intervene and set the decision-making process back on track. A child's best interests ought not be compromised by her parents' inability to protect those interests.

4.4.1(b) Opposition to Treatment Preferences

In the above case, the child and parents agreed on the treatment preferences. Cases may also arise at the apprentice stage where the child disagrees with her parents' treatment preferences. At the expert stage, parents may disagree with the final decision reached by their child.

In the case of the apprentice child, parents and health care providers ought to address opposition with the same seriousness as their own potential opposition. However, discussion, explanation, and debate ought not continue until the conflict can be resolved because preventing the child's access to treatment could become dangerous, particularly at certain stages of the illness. In the case where the apprentice child maintains her opposing position, even after what is considered to be sufficient explanation and discussion, the traditional steps ought to be taken and the courts or a representative thereof should be introduced to encourage and mediate the decision-making process.

The same solution applies to the case where the expert-child's parents disagree with her final decision. Because the expert-child has the right to veto any or all of her parents' suggestions, the onus of proving that her decision is wrong is placed on her parents. They would have to prove to the courts that either they were mistaken about the child's expert status or that, despite her status, her decision is flawed or wrong. Nonetheless, the traditional means of mediating such conflicts using court appointed representatives would be appropriate here, as it is in the case of disagreement between parent and apprentice-child.

4.4.2 Expanded Responsibility Burdensome to Health Care Workers

Health care workers may find the expanded responsibility placed upon them as most cumbersome. In insisting that children be included in the decision-making process, I have also included the role of informing the child (that is, not just telling but explaining and ensuring understanding) in the health care worker's job description. Because every child and every cognitive stage is different, this process may be difficult and time consuming. Health care workers serve many patients at the same time. Understandably, it is not ideal to be faced with three different patients with different cognitive abilities who all need to understand about Hodgkin's disease. What this requires is preparation and creativity. By taking the time to learn about childhood development and communication skills, health care workers will have a head start on the task with which they are faced. Generally, seminars that aim to educate doctors on different ways of effectively communicating with child-patients would be helpful. Again, these seminars are time-consuming, but I believe that health care workers who are committed to positively contributing to their patients' development will be willing to make the time and put in the effort. My response to the health care workers' objection is that the benefit to the patient outweighs the cost to the health care professional.

The health care workers must accommodate the expert child-patient because it is her right to make decisions about her own body. Health care workers inform and deliberate with adult patients to ensure that informed decisions are made. It is because of their right to autonomy that the time and effort must be spent. The same is true for the expert child-patient. Time and effort ought to be spent as an investment in the child's future and in the development of her autonomy and ability to make informed choices.

4.4.3 Expanded Responsibility Burdensome to Parents

Parents may find it difficult or even burdensome to balance their own lack of understanding about the diagnosis and possible treatments with the understanding of their child. Parents will be forced to deal with their own feelings about their child being sick and their need to understand the diagnosed illness, while also attempting to explain the situation to their child. At the same time, parents must assess the potential effects that the diagnosis and treatments will have on their other children as well as on their personal interests and responsibilities.

This provides a self-check for the parents and for the health care workers. Perhaps, if parents are finding it difficult to explain the situation to their child, then the parents themselves are not yet adequately informed to act as proxy consenters and they could return to the health care workers for further information and guidance as they would if deliberating a decision on theirown behalf. General education in child-development and in child-rearing may also be valuable in this type of situation. Parents ought to have the foresight to learn about the different aspects of childhood that could aid them generally in being parents and specifically as proxy consenters. Health care facilities also ought to aid in this process, not only by having the foresight to educate their professionals but also by offering courses and seminars to parents, prospective parents, social workers, and primary health care providers. Even if parents do not have the foresight to learn about development and child-rearing, advisors or consultants who have been trained to help surrogate decision-makers and who are knowledgeable about childhood development, illness, and treatment options, could also be made available for parents by health care facilities. Such tools may enhance parental ability to make decisions that are in their child's best interests and help the child make decisions for herself.

4.4.4 Expanded Responsibility Burdensome to Child-Patient

My approach may be argued against as being impractical on the grounds that it may be burdensome to the sick child. The intense participation of the more experienced child may be especially difficult. The expert child holds such status because of a long history of being ill. As previously explained, the more chronic, or the greater the duration of the illness, the more of an "expert" the child-patient becomes. I advocate that the child actively participate in the decision deliberation but that participation also be illness-appropriate. If the child is simply too ill to participate, then the parents along with the health care worker should decide that her developing capacities are compromised. In such a case, it is the parents' job to do the best they can to replicate the decision that would be made if their child could participate or decide for herself.

CHAPTER V

CONCLUSION

My aim in writing this thesis was to show that, contrary to traditional belief, some children are able to contribute in the making of decisions about their personal care. Based largely on empirical evidence, I argued that chronically and terminally ill children above the age of six generally have developed skills and capacities pertinent to autonomous decision-making. Because of these children's familiarity with their bodies, ailments, health care workers, and with many of the other factors that contribute to their care and well being, these children should be considered to be "experts."

Employing the line of reasoning that it is experience more than chronological age that contributes to autonomy, I argued that all children over the age of six ought to participate in decision-making to some degree. One is not born with the experiences and hence the abilities that aid in autonomous decision-making. Children gain such experiences over time, and subsequently, their abilities and capacities are also developed over time. By being encouraged to make decisions and exercise relevant skills and abilities, children fine-tune the skills needed for fully autonomous consent.

Along with the child's right to safeguarded interests, parents have the responsibility to safeguard those interests. Although some children may have enough experience within a specific domain to competently assess options within that domain with respect to their best interests, most children are not experienced enough within a specific domain to be able to make extensive moral decisions autonomously. Because of this lack of experience with specific domains, the responsibility of solving moral dilemmas typically ought to be transferred to parents. In cases where the child has shown to have gained extensive experience with a specific domain, and thus has become an expert within that domain, the child ought to make moral decisions on her own behalf.

Finally, I presented an approach for use in clinical practice that I argued will reconcile the needs and abilities of chronically and/or terminally ill children with the responsibilities of parents as set forth in theory and in law. With use of this model, children at all stages of chronic or terminal illness can exercise their abilities, fine-tune those skills they have yet to master, and further develop a sense of autonomy.

There are broad implications to this model that extend outside of the medical context. There are areas other than medicine in which some children will have attained expert status. In this thesis I focus on two non-medical areas, chess and tennis, in which children have achieved expert status. These two areas are relatively non-controversial and non-moral in nature. However, there are areas that are moral and controversial in nature. One example of such a context is education. There is often debate over whether or not a child who seems particularly bright ought to skip a grade or ought to enter a "gifted" more specialized program. Due to her experiences in the classroom, the child in question may be more of an expert on her educational needs than her parents, and therefore she would be more qualified than her parents to make the decision about whether or not she requires an alternative educational plan. Another such context is child custody. A child whose parents are divorcing may be more qualified than her parents to decide which parent she ought to live with. Because of her experiences living with both her parents before they divorced or with either or both of her parents singularly, the child may have developed a mature understanding of her own needs and how each parent will meet them.

Children may be more qualified than their parents to make certain moral or non-moral decisions due to their expertise in a specific area. Parents will likely have an easier time accepting that their children have gained more expertise in areas such as sports or the arts than they will accepting that their children have gained more expertise in more controversial and moral contexts. This is because traditional positions about the status of children, parents, and about the relationship shared by these two groups are challenged. According to this new approach, children are no longer necessarily deemed incapable of autonomous decision-making and parents are no longer necessarily most qualified to make all decisions on their children's behalves.

NOTES

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[6] Nichomachean Ethics. 1180a 2.

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[11] Some Thoughts Concerning Education. §66.

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[14] Some Thoughts Concerning Education. §41.

[15] Some Thoughts Concerning Education. §41.

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[17] An Essay Concerning Human Understanding. I, ii, §15, see also; Archard 88.

[18] An Essay Concerning Human Understanding. II,i, §22.

[19] An Essay Concerning Human Understanding. II, i, §15.

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[24] Rawls 463.

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[28] Rawls 469.

[29] Rawls 470-71.

[30] Rawls 469.

[31] Rawls 473.

[32] Rawls 473-74.

[33] McGowan Tress 27.

[34] Nichomachean Ethics. 1252b 13.

[35] Nichomachean Ethics. viii 12.

[36] Nichomachean Ethics. 1160a 32; 1169b6; 1170b 5-14.

[37] Nichomachean Ethics. 1166a1 1-10.

[38] McGowan Tress 30, for primary reference see EN Book 8 Chapter 8.

[39] Nichomachean Ethics. 1160a 32; 1169b6; 1170b 5-14.

[40] Locke, John. Two Treatises of Government. Ed. Mark Goldie. (Vermont: Charles E. Tuttle, 1993) II, vi, §55.

[41] Two Treatises of Government. II, vi, §65.

[42] Two Treatises of Government. I, vi, §56; II, vi, §63 and §67.

[43] see Rawls 395-588.

[44] Rawls 284.

[45] Rawls 463.

[46] Rawls 463.

[47] Rawls 465 –466.

[48] Rawls 496.

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[52] See the Quebec Public Health Protection Act, R.S.Q., c.P-35.

[53] See the Medical Consent of Minors Act.

[54] Infants Act, R.S.B.C., 1996 c. 223.

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[62] According to Professor Howard Black, email to the author, 12 April 2000.

[63] Black.

[64] Black.

[65] Lazar, *et al.* see also; United Nations Convention on the Right of the Child, Princple 2; Ontario's Child Welfare Act, Section 2.

[66] Lazar, *et al.*

[67] Lazar, *et al.*

[68] Danuta Bukatko and Marvin W. Daehler, Child Development: A Thematic Approach Boston: Houghton Mifflin Company, 1995) 262.

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[94] See Gabarino, *et al.* and Bluebond-Langner 169-171.

[95] Bluebond-Langner 182-197.

[96] Bluebond-Langner 182-197.

[97] Bluebond-Langner 174-182.

[98] Bukhato and Daehler 460-464.

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[100] Lazar *et al.*

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[109] Friedman Ross 106.

[110] See Dueck (Re) (1999) S.J. No. 143 1-9, pars. 1-17, and Dueck (Re) (1999) S.J. No. 144 1-6, pars. 1-13.

[111] Dueck (Re) No. 144, par. 6.

[112] Dueck (Re) No. 144, par. 10.

[113] Dueck (Re) No. 143, pars. 9-11.

[114] Dueck (Re) No. 144, par. 6.

[115] Dueck (Re) No. 143, par. 11.

[116] Dueck (Re) No. 143, par. 11.

[117] Dueck (Re) No. 143, par. 14.

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