

## ABSTRACT

### Autonomy or Beneficence: An Analysis of End-of-Life Care in Pediatric Patients

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Autonomy and beneficence are two core principles of biomedical ethics. However, autonomy, the patient's right to decide what he or she wants regarding medical care, can often conflict with beneficence, what the doctor believes is in the best interest of the patient. In addition, pediatric cases are more difficult, because there is a third party, the parents, involved in the decision-making process. Through literature review, this thesis analyzes how autonomy and beneficence may conflict in pediatric end-of-life care cases. Furthermore, the thesis examines how a type of autonomy, called relational autonomy, can assist in making decisions in these pediatric end-of-life care cases. In relational autonomy, parents are the driving force in the decision-making with the help of the medical staff. Parents must be strong advocates for their children. Finally, the Touchpoints program, developed by Dr. T. Berry Brazelton, is evaluated as a method of minimizing conflict between parents and physicians as parents strive to advocate for their children.

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AUTONOMY OR BENEFICENCE: AN ANALYSIS OF END-OF-LIFE CARE IN  
PEDIATRIC PATIENTS

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## DEDICATION

I dedicate this thesis to my brother Andrew, who passed away from cancer at the age of four, and to my parents, Mark and Melissa Nelson, who passionately advocated for him through his illness.

## CHAPTER ONE

### Introduction

#### *Principles and Virtues In Medicine*

##### *Overview of Principles and Virtues in Medical Practice*

It is a commonly held notion that the practice of medicine requires intelligence in order to succeed. Yet, medicine requires significantly more than just an intelligent mind that can work through the obstacles of ambiguous medical cases. Medicine can be divided into two main parts: the natural sciences and human interaction. Both are necessary in order to succeed in medicine. However, the moral aspect is fundamentally what makes medicine unique from other areas of science and business. Medicine can be described as moral because “it is at heart a moral enterprise and its members are bound together by a common moral purpose” (Marcum, 2012, pg. vii). James A. Marcum discusses why these virtues and ethical responsibilities are so important and how medicine is more than just natural science in the preface of his book, *The Virtuous*

*Physician* (2012):

The relationship is moral since the ethical mandate of medicine, with respect to the physician’s action, is to help—and not to harm—the patient. To harm the patient, either intentionally or unintentionally, is to fail at medicine’s primary ethical mandate that dates back to Hippocrates. For both the patient and society call upon the physician to benefit the sick and dying and to assist in the healing process. From this perspective, both the natural and social sciences support the practice of medicine but do not define it. Thus, the physician’s behavior, whether good or bad, is not peripheral to the clinical encounter but at the heart of what it means to be a healthcare provider (pg. vii).



Defining the term virtue is no small or simple task. The term virtue is a complicated term that does not have a clear-cut definition. The idea of virtue began with the Greek philosophers. For example, Plato believed that virtue was “knowledge of the excellence of the good life...definable by the degree to which they conformed to the pure forms” (Pellegrino, 1993, pg. 4). Aristotle defined virtue as “not just a feeling about what is good, or a capacity to make a good choice...but a habitual disposition to act well” (Pellegrino, 1993, pg. 5). For Aristotle, virtue could be habitual by training and practice. Building on Aristotle’s definition, Aquinas believed that virtue was teleological, meaning that the acts of a person during the course of his or her life were oriented to his or her specific end. Aquinas believed that there were two categories of virtues, natural and supernatural, and that these complemented each other. The natural virtues came through practice, whereas the supernatural virtues were directly aimed toward God as their end. Because the end, according to Aquinas, was spiritual, the only way one could practice the natural virtues was through supernatural virtues (Pellegrino, 1993, pg. 8). Although there are numerous definitions for virtue, the definitions of Aristotle and Thomas Aquinas are what well-known bioethicist and physician Edmund D. Pellegrino uses when discussing virtue.

Although there are numerous virtues that a physician must have, Thomas Beauchamp and James Childress founded the four core principles that are most influential in medical practice. The four core principles are autonomy, beneficence, non-maleficence, and justice (Pellegrino, 1993, pg. 52). This chapter will discuss the meaning of these principles and how each of these principles is necessary for a physician. Although these principles are discussed individually, in all reality they are interwoven to

ultimately obtain the ends of medicine as originally described by Aristotle. The ends of medicine are defined as

...The restoration or improvement of health and, more proximately, to heal, that is, to cure illness and disease or, when this is not possible, to care for and help the patient to live with residual pain, discomfort, or disability (Pellegrino, 1993, pg. 62).

In addition, this chapter will look at the idea of paternalism and how it conflicts with the principle of autonomy.

### *The Principle of Autonomy*

Autonomy originates from one of the core principles created by Beauchamp and Childress. Autonomy, in its simplest definition, is the ability of the patient to make decisions without the influence of others (“Autonomy”, 2007). Beauchamp and Childress discuss autonomy and the need for respect for autonomy in their book, *Principles of Biomedical Ethics* (2013):

To respect autonomous agents is to acknowledge their right to hold views, to make choices, and to take actions based on their values and beliefs. Such respect involves respectful action, not merely a respectful attitude. It also requires more than noninterference in others’ personal affairs. It includes, in some contexts, building up or maintaining others’ capacities for autonomous choice while helping to allow fears and other conditions that destroy or disrupt autonomous action. Respect, so understood, involves acknowledging the value and decision-making rights of autonomous persons and enabling them to act autonomously, whereas disrespect for autonomy involves attitudes and actions that ignore, insult, demean, or are inattentive to others’ rights of autonomous action (pg. 215).

Autonomy has become the preeminent principle. Previously, the concept of paternalism, or “doctor knows best” model, reigned over the patient’s autonomy. The doctor would evaluate the patient and make decisions on how the patient should be treated or receive information based on his or her knowledge (Beauchamp & Childress, 2013, pg. 214). However, as Beauchamp and Childress alluded to in this quote, society

has acknowledged the fact that patients should have the right to decide their course of treatment along with the help of the doctor. Because the patient holds certain values as the result of his or her culture or religion and the doctor has the knowledge and expertise in medicine, the relationship should be equal. It is up to both the patient and the doctor to respect one another's thoughts and opinions (American Academy of Pediatrics Committee on Bioethics, 1995, pg. 314).

The fact that providers must respect the values and customs of their patients engenders both positive and negative obligations. Positive obligation of autonomy involves disclosing all information to the patient and helping to guide them to make autonomous decisions. Because the nature of the patient-physician relationship is fiduciary, it is imperative that the provider discloses all of the information so that the patient can make an autonomous decision for himself or herself. The idea is that the patient should not be dependent on the physician but rather the patient should make decisions that fit with his or her cultural views after receiving all of the information.

On the other hand, negative obligation forces providers to not interfere and control the decisions of their patients. The patient deserves the right to make decisions over his or her own body. Although negative obligation usually prevails, two exemptions to this obligation exist. The first exemption is if patient is causing harm to himself or herself or to other persons. In this case, the provider can and should interfere with the decisions of the patient (Beauchamp & Childress, 2013, pg. 107). The second exemption occurs if the patient does not have the mental capacity to make decisions (American Academy of Pediatrics Committee on Bioethics, 1995). This is the case in pediatric

patients, mentally disabled patients, and some elderly patients who do not have cognitive ability.

Autonomy has become one of the most important principles in medical practice. In a society that wants to be in-control, it is no surprise that the concept of autonomy has surpassed that of paternalism. Chapter Two will demonstrate how autonomy can be hazy in pediatric end-of-life care cases and how the provider must handle situations where the patient is not the one with the autonomy.

### *The Principle of Beneficence*

One of the major conflicts in medical ethics is the conflict between autonomy and beneficence (Beauchamp & Childress, 2013, pp. 214-215). Beneficence is defined by Pellegrino as “preventing harm, removing harm, and doing good.” A common belief stands that beneficence is the same as paternalism. Pellegrino comments on the differences between paternalism and beneficence in his work, *Virtues in Medical Practice* (1993):

First of all, beneficence and paternalism are not synonymous. Paternalism (or maternalism) assumes that the physician knows better than the patient what is in the patient’s best interests, or that even a mentally competent patient cannot possibly know enough about the choices to be able to make intelligent decisions...Beneficence and its corollary, nonmaleficence, require action to advance the patient’s interests, or at least not harming them (pg. 58).

According to Pellegrino, because the nature of beneficence is to help the patient and paternalism violates the true nature of beneficence, paternalism cannot be beneficent (1993, pg. 58).

Although according to Glenn Graber and David Thomasma in their book *Theory and Practice in Medical Ethics*, beneficence falls under the umbrella term of paternalism.

Graber and Thomasma state that beneficence is “the element of paternalism that seeks the good of the other person” (Graber and Thomasma, 1989, pg. 31).

Beneficence can be broken down into a hierarchy in order to respect the patient’s autonomy: (1) what is medically good for the patient to be able to function psychologically and emotionally; (2) what is good for the patient in relation to what he or she feels is good based on their cultural or religious values; (3) what is good for the person as a human being in society; and (4) what is good for the person in a spiritual sense (Pellegrino, 1993, pg. 58). Providers must recognize that under the Hippocratic Oath, they are legally and morally responsible for helping to provide a cure or palliative care for their patients. However, this must be done in a way that does not interfere with what the patient wants or believes. This can be accomplished if there exists a balance between beneficence and autonomy. Graber and Thomasma (1989) describe the balance as this:

Instead of asking physicians to abandon their historical position of beneficence (cum paternalism) they call for a balancing of this principle with a principle of autonomy (which they recognize physicians will find having a certain normative pull on their thinking already, and which they make even more palatable by interpreting it as an alternative approach to ascertaining the patient’s best interests—this from the patient’s point of view). In this way, physicians need not view themselves as abandoning their historical allegiance to beneficence when they take into account the wishes of the patient (pg. 59).

This quote corroborates the fact that beneficence should not be seen in direct conflict with autonomy. The principle of beneficence should be balanced with autonomy so that the provider may honor his or her duty to the patient, and the patient still holds autonomy.

Beneficence, being one of the core principles, is extremely important and crucial in medicine. Although providers may feel that it is difficult to balance beneficence with autonomy, it is necessary for a strong patient-physician relationship. The concept of

beneficence correlates with another core principles, nonmaleficence, which is discussed in the next section.

### *The Principle of Nonmaleficence*

The principle of nonmaleficence is fundamentally similar to that of beneficence. Where beneficence is acting in a manner in which to benefit the patient, non-maleficence is acting in a manner that does no harm to the patient. These principles must remain separate, as there are instances in which a provider must continue to act with non-maleficence but has no obligation to beneficence.

In order to ensure that providers act with non-maleficence, a thorough and lengthy education process about not only scientific and medical topics but also topics such as psychology, sociology, and medical ethics is necessary in order to be able to effectively communicate with a patient. Providers must remember that each case is unique. An article by Raanan Gillon from the *British Journal of Medicine* (1994) analyzes this concept.

We need to ensure that we can provide the benefits we profess (thus “professional”) to be able to provide. Hence we need rigorous and effective education and training both before and during our professional lives. We also need to make sure that we are offering each patient net benefit. Interestingly, to do this we must respect the patient’s autonomy for what constitutes benefit for one patient may be harm for another. For example, a mastectomy may constitute a prospective net benefit for one woman with breast cancer, while for another the destruction of an aspect of her feminine identity may be so harmful that it cannot be outweighed even by the prospect of an extended life expectancy (pg. 185).

It is evident in this statement that each principle does not stand on its own. In order to act with non-maleficence, it is imperative that providers respect the patient’s autonomy.

Additionally, providers must analyze the risks and outcomes to determine whether a specific treatment plan is the best option. This requires the provider to not only

calculate the probabilities and risks for that certain procedure or treatment but also to communicate well and get to know the patient (Gillon, 1994, pg. 185). This aspect becomes extremely relevant when dealing with pediatric patients, especially cancer patients. For example, the health provider must determine how much chemotherapy and radiation the child can handle.

One approach that can help providers act in a non-maleficent manner is to use the Principle of Double Effect. There are four parts to this act:

(1) The action itself must not be intrinsically wrong; it must be a good or neutral act. (2) Only the good effect must be intended, not the bad effect, even though it is foreseen. (3) The bad effect must not be the means of the good effect. (4) The good effect must outweigh the evil that is permitted (“The Principle of Non-Maleficence”, 1998).

By using this technique, providers can determine whether or not the act is beneficial rather than maleficent on a case-by-case basis.

Because non-maleficence happens to be so similar to beneficence, many people place these two principles into the same category. Although the nature of these two concepts seems alike, in reality they are different. Non-maleficence requires physicians to do no harm to their patients by refusing to be negligent and focus on what is best holistically for the patient. Beneficence requires physicians to prevent harm and do whatever it takes to benefit the patient. The upcoming chapters will discuss how non-maleficence plays a role in the dynamic of physicians treating pediatric patients when their treatment plan may differ from the treatment plan the parents’ request.

### *The Principle of Justice*

The fourth principle in the series of principles essential to medicine is the principle of justice. Justice, as expressed by the *British Medical Journal*, can be defined

as “the moral obligation to act on the basis of fair adjudication between competing claims” (Gillon, 1994, pg. 185). Justice is crucial to maintaining a smooth-running, peaceful community; for without justice, our world would cease to exist, and violence would abound. In his book, *The Virtues of Medical Practice*, Pellegrino states (1993):

On the view of the virtues, however, justice has its deepest roots in love. It is an extension of the charity we should show to others. Not to do justice would be to relapse into self-interest, to turn from love of the other to love of self. Love testifies that the claims of others upon us are the claims of our brothers and sisters in a community of compassion and care. By that fact, individuals are entitled to be loved, especially in health care settings...As St. Augustine held, justice is the concern and love that individuals in a community must show to others (pg. 94).

To reiterate what Thomasma said justice plays a vital role in the health care setting. Not only patients but everyone the medical staff encounters, such as parents, drug companies, insurance companies, and the like deserve to be treated in a just manner.

Justice is probably the most complicated principle out of the four principles essential in medicine. Justice is not just a principle but also a virtue. In the virtuous sense, justice is a character trait in which a person habitually delivers what is due to every patient. As a principle, justice requires a person to give a person what she is due and to treat all cases equally. In essence, justice is a culmination of the previous three principles discussed. Justice requires that a physician do no harm (non-maleficence), respect the patient’s autonomy, and do what is best for the patient whenever possible (beneficence) (Pellegrino, 1993, pg. 96). Justice can be divided into three categories: fair distribution of scarce resources (distributive justice), respect for people’s rights (rights based justice), and respect for morally acceptable laws (legal justice).

Because we live in a world with limiting resources, it is important that physicians be socially responsible with the available resources. For example, if a doctor has a patient



in which a treatment may or may not be beneficial, it is important for the said doctor to judge whether this case is the best use of the treatment. If that patient has significant financial issues and the treatment has a low rate of success, it would be more beneficial for the doctor to withhold the treatment than to administer it. In each case, the doctor must look at all aspects of the situation in order to minimize unequal distribution and avoid wasting resources.

In order to practice rights based justice, physicians must respect the rights of their patients. For example, a patient may engage in sexually promiscuous activity and may have acquired HIV. If this patient comes to the clinic asking to be treated, it is not acceptable for the doctor to refuse simply based on his or her disagreement with the patient's lifestyle. The physician must treat all patients equally, whether or not he or she condones the choices they make. If a doctor does otherwise, this could be considered an act of discrimination.

Finally, physicians must obey the morally acceptable laws of society. For instance, if a physician is treating a child that has been abused, it is the responsibility of the doctor to report this case to the police, even if the child wants the matter to stay confidential. Although most of the time the doctor must remain faithful to the wishes of confidentiality of the patient, child abuse is one instance where the doctor must break this because of his or her obligation to follow the laws of society as well as the moral virtues of medicine (Gillon, 1994, pg. 185).

Justice is extremely important in medical practice especially when it comes to the patient-physician relationship. As discussed earlier, justice should be a "loving justice" when it comes to healing. In this case, the physician should always put the patient first.

This requires the physician to hold a fiduciary relationship with the patient and not take advantage of this trust for personal benefit. The physician must suppress his or her need for self-interest and personal preferences in order to best serve his or her patient (Marcum, 2012, pg. 82).

Overall, justice could be described as the virtue that encompasses all other virtues; for without justice there would be no beneficence, non-maleficence, or patient autonomy. A just physician puts his or her patient's needs before his or her own and allocates resources in a way that benefit the patient medically and economically.

#### *Paternalism and its Conflict with Autonomy*

Paternalism is defined as “the intentional overriding of one person’s preferences or actions by another person, where the person who overrides justifies this action by appeal to the goal of benefiting or of preventing or mitigating harm to the person whose preferences or actions are overridden” (Beauchamp & Childress, 2013, pg. 215). This principle has been around for many years. “The *Oxford English Dictionary (OED)* dates the term paternalism to the 1880s, giving its root meaning as the principle and practice of paternal administration; government as by a father; the claim or attempt to supply the needs or to regulate the life of a nation or community in the same way a father does those of his children.” Paternalism used to be the common standard in medicine. Patients would come to the doctor and expect that the doctor knew what he was doing; therefore they did not see a need to assert their autonomy. But today, patients do exert their autonomy. Because patients are beginning to assert this autonomy, this has created conflict between the two values of autonomy and paternalism (Beauchamp & Childress, 2013, pg. 214).

Even though paternalism can be beneficial, autonomy is now recognized as more important and something that should be valued. Because of the boom in technology it is now possible for patients and family members to become modestly educated on medical issues.

Although autonomy typically overrules paternalism in medical practice, there are cases in which paternalism is acceptable and should be implemented. For example, in emergency situations the goal is to act quickly in order to save the patient's life. In these situations, it can be difficult to gain informed consent and determine the best treatment plan. The physician must decide what he or she believes will be best to save the patient (Post, 2004). In addition to this, Beauchamp and Childress discuss in their book *Principles of Biomedical Ethics* (2013) five conditions in which paternalism should rule over autonomy. These conditions include:

1. A patient is at risk of a significant, preventable harm
2. The paternalistic action will probably prevent the harm
3. The prevention of harm to the patient outweighs risks to the patient of the action taken
4. There is no morally better alternative to the limitation of autonomy that occurs
5. The least autonomy-restrictive alternative that will secure the benefit is adopted (pg. 222)

Based on these conditions, the only time paternalism should undermine autonomy is when the patient's plan could somehow harm him or her or if the patient is in an emergency situation in which there is no time to determine what the patient wants.

In general, paternalism has been replaced by autonomy in the medical field. However, there are still physicians who believe that paternalism should dominate in medical practice due to the fact that physicians have the medical education. It is for this reason that the two principles often collide. It is widely accepted, though, that patients do

in fact have a right to determine what happens to them and the treatment they undergo. In order for an effective and beneficial patient-physician relationship, these two principles must be balanced. Future chapters will discuss a type of autonomy that allows doctors to voice their opinions but also ensures that patients continue to hold on to their autonomy.

### *Conclusion*

There are four main principles in medical practice as described by Beauchamp and Childress: autonomy, beneficence, non-maleficence, and justice. Although there are many more principles necessary in medicine, these principles are essential in maintaining an ethical and beneficial patient-physician relationship. Although each principle has a unique definition, they are all interconnected. The following chapters will discuss how each of these principles plays a role in end-of-life care in pediatrics, specifically of children under or around the age of seven. This age is important, because children over this age have the cognitive ability to contribute to their medical decisions.

Pediatrics is a unique field in which not only is the physician dealing with the patient, the child, but also the child's advocate, usually the parent. These principles, especially autonomy, become incredibly important and necessary as the physician must treat the patient with what he or she believes is best, but also recognize that the parent knows his or her child better than anyone. It therefore requires a balance of these principles, especially autonomy and beneficence, in order for the child to receive the best possible treatment.

Virtues are also important in medicine. Some of those virtues include compassion, phronesis, prudence, justice, fortitude, temperance, integrity, and self-effacement.

Pellegrino examines how these virtues complement the four core principles in *The*

*Virtues of Medical Practice*. He states, “We agree with the general conclusion that virtue and duty-based theories complement each other. Each does provide a different and complementary perspective on moral choice and action” (Pellegrino, 1993, pg. 25). Pellegrino’s idea is that principles must be understood through the concept of virtue. The Touchpoints theory, which will be discussed in Chapter Four, analyzes how physicians and parents can work together for the benefit of a child. Although not explicitly stated in this theory, the concept of virtue can be seen in the Touchpoints theory used to help treat pediatric patients.

## CHAPTER TWO

### Implications of Autonomy and Beneficence

#### *Who Makes the Decisions and How?*

##### *Introduction*

As described in the previous chapter, there are four major principles as defined by Thomas Beauchamp and James Childress: autonomy, beneficence, non-maleficence, and justice (Pellegrino, 1993, pg. 52). Although these principles overlap for the most part in medicine, there are two principles that can sometimes conflict: autonomy and beneficence. This chapter will focus on these two principles describing how they conflict and the perspectives of each side: the patient/family and the medical staff.

##### *Autonomy*

Autonomy is defined as the ability of a patient to make decisions without the influence of others (“Autonomy”, 2007). This definition stands when it comes to cases involving competent adults; however, the case of autonomy in pediatrics differs from that of adults. Because children do not possess the cognitive capacity to make decisions, the parent or guardian must act as the surrogate in making medical decisions that benefit the child. The *Journal of Clinical Oncology* (Hord et al., 2006) discusses the right of parents to make decisions in pediatric cancer cases:

In cases involving children, respect for autonomy is not seen in the same manner as in adults because young children often are not felt to have decisional capacity, which is prerequisite for autonomy. As children mature and enter the teen years, they usually develop capacity, and their input related to health care is often sought, acknowledged, and respected by their parents as well as their health care providers. However, unless the child has been declared emancipated by a court of

law (i.e., deemed to possess competence), it is the parent or guardian who theoretically exercises autonomy on behalf of their child. In such cases, proxy decisions should strive to be a “reasonable presumption of the child’s wishes” even though such wishes may not be known.

Because of this lack of cognitive ability in the patient, families must step in to decide what they believe is best. Unfortunately, there are circumstances in which the family’s wishes may differ from those of the medical staff. Deciding which person should make the final decisions regarding the treatment regimen can be a very difficult endeavor, but there are ways to incorporate the wishes of the family with the guidance and help of the medical staff.

Although autonomy in general is extremely important in medical practice, there are instances in which parents may not have the patient’s best interest in mind. The following sections will discuss factors, both good and bad, that can influence the decisions made by the family on behalf of its child.

#### *Relational vs. In-Control Agent*

Autonomy can be further broken down into two categories: in-control agent autonomy and relational autonomy. Jennifer K. Walter and Lainie Friedman Ross from the *Official Journal of the Academy of American Pediatrics* (2013) describe these two types of autonomy in one of their articles:

Reliance on an individualistic conception such as the “in-control agent” model prioritizes self-sufficiency in decision-making and highlights a decision-maker’s capacity to have reason transcend one’s emotional experience. An alternative model of autonomy, relational autonomy, highlights the social context within which all individuals exist and acknowledges the emotional and embodied aspects of decision-makers (pg. 16).

There are several differences in these two types of autonomy. In-control autonomy focuses solely on the freedom of the patient’s surrogate (in this case the

parents). Outside influence is not typical, because it is the responsibility of the family to choose what is right for its children (Walter & Ross, 2013, pg. 22).

On the other hand, in relational autonomy the doctor can think rationally, but also empathetically when the family may be thinking emotionally due to the intimacy of the situation. The family can be in control but also utilize the knowledge of the medical staff that can help influence the family into making the wisest treatment options. Finally, this model takes into account the wishes of the patient when the patient is of reasonable age (Walter & Ross, 2013, pp. 18-23).

#### *Advantages of In-Control Autonomy*

In-control autonomy does include some advantageous aspects. One reason this model has managed to flourish is the fact that it emphasizes the individualistic nature of families and allows them to make decisions based on the views of their culture without the doctor interfering. Because this model requires the medical staff to disclose all aspects of the diagnosis and treatment plan, parents can utilize the information disclosed to make the decision they see fits best for their child. This model is extremely important for families who have a very strong tie to culture or religion. The medical staff can disclose medical information, but then the parent ultimately decides the treatment regimen based on his or her beliefs. For example, a clinician would not interfere if the family strongly believes in the cessation of chemotherapy. Chapter Three will discuss how religion can play a crucial role in the decision-making process.

In addition to allowing the family to be independent, this model encourages rational and sensible decisions over emotional ones. The medical professional should provide only facts with no opinions or suggestions. The parents then take this information



and make a rational decision that will be best for their child while suppressing their natural emotional responses (Walter & Ross, 2013).

#### *Disadvantages of In-Control Autonomy*

There are a few disadvantages when it comes to the in-control autonomy model. First, a significant issue with this model is the fact that the provider cannot implement his or her own suggestions at all. Parents do know their child better than any other person; however, they lack the medical knowledge of a medical professional. Therefore, the parent may make a decision that may not be medically beneficial for the child.

Second, this model emphasizes rational thinking over emotional thinking, but it is somewhat unrealistic. The majority of parents have an unconditional love for their children. They do not want to see their child enduring pain and suffering from an illness or injury. Therefore, when these unfortunate circumstances are the case, parents are bound to become at least somewhat emotional, making decision-making difficult.

Finally, although this model may be beneficial for strong-willed people or people with a strong cultural or religious tie, physicians who practice by this model believe that the parent is “on their own and should be able to think clearly about an illness.” This may be too much to ask for someone who is truly struggling with the situation. Physicians should be there to help guide these uncertain parents, which is where relational autonomy comes into play (Walter & Ross, 2013).

#### *Advantages of Relational Autonomy*

The relational autonomy model has many advantages. First, physicians, other family members, and other medical staff are encouraged to be a part of the decision-making process. Because parents are not necessarily medically trained, their decisions

may not be medically best for their child. Parents do know their child better than anyone else, but the doctors know the clinical situation. This model allows physicians to be a part of the process to help guide the parents in their decisions. In addition, part of a physician's moral obligation is to be there to care for the emotional needs of the child and the family. This model encourages the physician to empathize with the child and family, in essence, to have a good bedside manner. The role of the physician is two-fold: to explain the medical facts about the diagnosis and treatment and also to be sensitive to the information the child and family are receiving.

Another aspect of relational autonomy is forgoing the narrow pathway of only looking at what is beneficial for the patient to look at the situation as a whole. When a physician treats an adult, there are only two real parties involved: the patient and the medical staff. The doctor can diagnose and suggest a treatment plan and the adult can choose to accept or refuse treatment; however, when dealing with a pediatric patient there are many parties involved: the medical staff, the parents, the child, and other family members, such as siblings, grandparents aunts, and uncles. This model considers everyone involved in the situation. (Walter & Ross, 2013).

Relational autonomy truly relates to the virtue of integrity from Pellegrino's book *The Virtues in Medical Practice*. This is what Pellegrino says about the virtue of integrity in decision-making between patients and physicians:

Under all ordinary circumstances, however, the formula for the most morally reassuring decision-making seems to be this: the decision should not be made by the physician for the patient, nor should it optimally be made by the patient in isolation from the doctor, even if this is phenomenologically possible. Rather, the decision should involve both doctor and patient in a true consensus in which the integrity of each person is protected. The physician should think of making a decision *for* and *with* the patient, "for" signifying not in place of the patient but in the interests of the patient (Pellegrino, 1993, pg. 133)

### *Disadvantages of Relational Autonomy*

Two issues surface regarding to relational autonomy. First, the parents must be open to the suggestions and guidance of the physician. Whereas most people welcome such input because of the daunting task of making decisions alone, some parents may view this as a disadvantage. If the family has strong ties to culture and/or religion, they may want to withdraw or refuse treatment. But in this model, the physician can have a say in things and can strongly encourage the family in the decision-making process. This model takes away from a family's ability to be completely autonomous.

Second, this model may be challenging for the physician. This model takes into consideration the family and the patient. However, a physician's primary role is the treatment and wellbeing of the patient, not the family. For instance, grieving is an important process, especially in end-of-life care. When the family discovers that their child has a terminal illness, they may choose to forgo treatment and bring the child home, so that they can grieve privately. Because relational autonomy allows the family to make this decision, there could be a conflict between the physician's desire for the good of the patient and the family's autonomy in wanting to bring their child home to grieve.

### *Informed Consent*

Informed consent is the doctrine that patients have the right to information about their medical condition in order to make an informed decision about whether to go through with or refuse treatment (Thornton, 2000, pg. 187). Thomas Beauchamp and James Childress discuss informed consent in their book *Principles of Biomedical Ethics*:

Two different senses of "informed consent" appear in current literature, policies, and practices. In the first sense, informed consent is analyzable through the

account of autonomous choice presented earlier in this chapter: An informed consent is an individual's autonomous authorization of a medical intervention or of participation in research. In this first sense, a person must do more than express agreement or comply with a proposal. He or she must authorize something through an act of informed and voluntary consent. In the second sense, informed consent refers to conformity to the social rules of consent that require professionals to obtain legally or institutionally valid consent from patients or subjects before proceeding with diagnostic, therapeutic, or research procedures. Informed consents are not necessarily autonomous acts under these rules and sometimes are not even meaningful authorizations. Informed consent refers here only to an institutionally or legally effective authorization, as determined by prevailing social rules (Beauchamp & Childress, 2013, pg. 122).

Because children are not competent enough to make decisions on their own, physicians who are treating pediatric patients must obtain informed consent from a parent or legal guardian ("Pediatric Decision-Making", 2008). According to an article from the *American Academy of Pediatrics* (1995) on informed consent, the following elements are crucial:

1. Provision of information: patients should have explanations, in understandable language, of the nature of the ailment or condition; the nature of proposed diagnostic steps and/or treatment(s) and the probability of their success; the existence and nature of the risks involved; and the existence, potential benefits, and risks of recommended alternative treatments (including the choice of no treatment).
2. Assessment of the patient's understanding of the above information.
3. Assessment, if only tacit, of the capacity of the patient or surrogate to make the necessary decision(s).
4. Assurance, insofar as is possible, that the patient has the freedom to choose among the medical alternatives without coercion or manipulation (pg. 315).

Although these are the basic elements of informed consent, each state can also determine laws relating to the amount of information needing to be disclosed.

Specifically in Texas, the physician is mandated to disclose the risks of medical procedures and must obtain the consent of the patient to legally perform a medical procedure. In the case of pediatrics, the medical staff must disclose the information to the parents and gain informed consent from them, since the parents will be the ones making

the decisions for the child. The law requiring the medical staff to obtain the patient's informed consent was officially instated in 1977 as Article 4590i, Section 6.01 *et seq.* of the *Texas Revised Civil Statutes Annotated*. The Texas Medical Disclosure Panel was created because of this statute to assess medical and surgical procedures. The panel decides whether specific disclosures of the procedure are required. If they are, the panel then determines what aspects of the procedure need to be disclosed. Once the panel assesses the procedures, they are placed on one of 2 lists. List A holds procedures that require disclosure and the specific disclosure required. List B holds all procedures that require no specific disclosure (Thornton, 2000, pg. 188). The lists with the procedures can be found on the Texas Department of State Health Services website.

### *Age of Reason in Pediatrics*

Age of reason is a complicated topic. In each country, there are different ages in which the country believes children have developed enough cognitive ability to make decisions. However, there is more to the situation than just age. The parents' judgment also plays a critical role in determining if a child is mature enough to handle inputting his or her own suggestions. Although each child is different, there are cognitive milestones that can serve as a guideline to determining about what age the child should be able to share his or her suggestions.

According to Jean Piaget, a clinical psychologist in childhood development, there are four stages of development: sensorimotor, pre-operational, concrete operational, and formal operational. The sensorimotor stage starts at birth and lasts until 18-24 months of age. In this stage infants become aware of the world around them. They search the world around them, putting things in their mouths, picking up toys, throwing toys, and so much

more. Around 7-9 months, they start to understand that objects exist even though they are not directly in front of their face. Finally, they begin to talk, which is the marker that they have moved to the next stage.

The next stage is the pre-operational stage and lasts until about age 7. In this stage, children's language begins to mature, and they begin to use their imagination. This stage is when they begin to play make-believe and start to understand past and future.

The concrete operational stage occurs between the ages of seven to eleven. In this stage, children go from an egocentric way of thinking to a more external mode of thinking. In this stage, children begin to think more logically and abstractly ("Piaget's Stages of Development"). Based on Piaget's stages, because children in the concrete operational stage are thinking more abstractly and logically, this seems like the most appropriate stage in which children are able to at least vocalize their input in their treatment regimen. This is a very rough estimate as children will mature at different rates, and parents must determine whether their child is mature enough to handle helping in the decision-making process. However, under normal circumstances, children between the ages of 7 and 11 should at least be able to participate in decisions with their parents. At this point, autonomy is no longer focused solely on the family but is balanced between patient and family.

The formal operational stage occurs at age eleven. The child is able use symbols related to abstract concepts in algebra and science. The child starts to formulate hypotheses, ponder abstract relationships, and think about multiple variables. This is the final stage of Piaget's four stages of development and continues into adulthood.

This thesis will focus on children under the age of 7 who are not yet at the age of reason.

### *Beneficence*

The previous sections have shown how crucial autonomy is in medical care. Beneficence is, in the most basic terms, doing what is best for the patient (Hord et al, 2006). In addition to doing what is best for the patient doctors must also demonstrate truthfulness, trustworthiness, and faithfulness. These virtues are crucial in the patient-physician relationship (Graber & Thomasma, 1989, pg.163). Most of the time patients want to do whatever will help them, and they follow the regimen the doctor suggests. There are times when the autonomy of the patient conflicts with the treatment regimen the doctor feels will best benefit the patient. In the case of pediatrics, the doctor may prescribe what he or she thinks is the right treatment plan, but the parents may retort by saying that they know their child best. Glenn Graber and David Thomasma explain this in their book, *Theory and Practice in Medical Ethics* (1989):

For example, the principles of beneficence and equality may tell us that the life needs and developmental needs of children ought to be met; but they do not, in themselves, tell us who ought to contribute to meet the needs of this particular child, nor do they tell me which child's needs I ought to contribute to meeting. These duties are "imperfect obligations" which dictate action of a general type but do not specify determinately how the duty is to be carried out. However, when this imperfect obligation is coupled with an established social institution of the family, a specific and stringent "perfect obligation" results: I have a duty to provide for my own child's needs; and each child can rightfully expect to have his or her needs met by members of his or her family. (pg. 55)

Unfortunately, these issues usually end up causing conflicts and being brought to an ethics board or even to court. The difficult part is that there are two parties who have certain obligations because of their roles, and therefore they feel that their solution is the

right one. Robert Veatch discusses this situation more in his book, *Case Studies in Medical Ethics* (1977):

Both physicians and parents normally believe that goods are not completely interchangeable. The physician has a special obligation, a contract, with his patient. Parents have a special obligation to their own children. If this is true, two moral problems remain. For the physician, the question is to avoid individualistic ethics. Especially in situations where the interests of one patient conflict with those of another, it is not helpful to say that the physician's duty is to his patient. For the parent, the question is how to serve the children's interests equally when those interests conflict. (pg. 87)

Typically, autonomy prevails over beneficence, especially in an era when parents have more access to information and the ability to research and know about the diagnosis and treatment of their child. Before information technology, many people believed in an idea called paternalism, the concept that "the doctor knows all." Patients usually followed the prescribed regimen for their child's illness with no hesitation or questions. Because access to information is abundant and education has developed further, more and more patients are researching their diagnoses online and hesitating when the doctor prescribes multiple drugs and therapies.

Since autonomy focuses on the patient and family's independence, beneficence often times conflicts with this principle, because the physician wants to do the best for his patient. Many times the patient or family and the doctor agree on what is the best treatment, and the patient follows the regimen the doctor prescribes with little to no input. When this is the case, beneficence and autonomy coincide. However, these principles begin to conflict when the doctor believes he or she has the best answer and the family believes differently. This is when there has to be compromise, education, and collaboration in the treatment plan rather than a conflict between principles.



The conflict between beneficence and autonomy is far from over. These two principles are vital, but they also create issues in the world of medical ethics. Although parents usually have the child's best interest at heart, there are times when this is not the case. The next section covers these situations in which parents should not be trusted in making decisions for their child.

### *Parental Desire for Child's Well-Being*

Although most parents genuinely are looking out for the best interest of their child, there are some parents who are not. As stated in the previous sections, most of the time it is important for the doctor to listen and communicate with the family and honor its autonomy in the clinical setting. But, when situations arise where this is not the case, physicians must assert their authority based on their judgment of the situation.

For example, it is possible that parents may have life insurance on their child. If the parents are not looking out for the child and are only interested in the money, their decisions regarding medical treatment may not be what is best for child. They may decide they want to forgo treatment, letting the child die to gain the life insurance. While this situation would be rare, it is one where the doctor must assert his or her authority in making the decision that best fits the child.

Another example of an issue regarding parental authority involves drug or alcohol issues. Parents involved in drugs and alcohol typically have lower education levels and therefore may not have the knowledge to best care for their children. When parents of these children come in with a child needing treatment, the doctor may have to thoroughly explain procedures and treatments with them, leading to a more paternalistic patient-physician relationship.

Finally, more commonly, are parents who lack mental stability. As stated earlier, coping with a child with a terminal illness is hard, no matter what mental state of the parents. If a parent is mentally unstable, his or her thoughts and ideas regarding treatment may be skewed. They may ask for every treatment possible, because they are not capable of dealing with the potential for loss. Or, they may decide to discontinue treatment altogether, taking the child home to privately cope. Both of these situations require a physician to carefully analyze the situation, which can be very difficult for even the most intuitive physician.

### *Conclusion*

When looking at Childress and Beauchamp's four core principles, two of those principles sometimes conflict: autonomy and beneficence. When doctors take the Hippocratic oath, part of that oath says to do no harm. This is the practice of non-maleficence in medicine. In pediatrics, that means looking out for the best interest of the child, especially in the case of unfit parents. Most of the time patients, or in the case of pediatric patients their parents, agree with the doctor and follow the suggestions the doctor gives for treatment. However, there are instances when the ideas of the parent do conflict with the doctor. Usually this has to do with a strong religious or cultural practice. The next chapter will discuss how various religions and cultures play a part in the medical treatment of children.

## CHAPTER THREE

### Implications of Religion and Culture on Autonomy

#### *How Does Religion Play a Role in Parental Decisions Regarding Their Child?*

##### *Introduction*

The previous chapter discussed the crucial roles of autonomy and beneficence in medicine. Although it is important for doctors and medical staff to encourage families to do what is best for their child medically, it is also important for them to respect how culture and religion may play a role in what the family sees is best for a child. What is unique in pediatric cases is there is that third party, the parents that determine what is best on behalf of the child. In adult medical cases, the relationship is between the physician and the patient, but with pediatrics, parents are also involved in the decision-making, and depending on the age of the child, may be the sole decision-makers in the treatment plan.

This chapter will analyze cases from four different religions and cultures that have strict rules when it comes to decision-making processes in treatment and end-of-life care. It is important that healthcare providers know the background of a child and his or her family and understand what their cultural or religious values before proceeding with treatment.

##### *The Church of Jesus Christ of Latter-Day Saints*

The Jesus Christ of Latter-Day Saints is a religion that was founded in 1830 by Joseph Smith. The members of the church believe that he retreated to the woods where God appeared to him instructing him to restore the original church of Jesus Christ. On

April 6, 1830, the first church was officially organized in Fayette, New York (“What do Mormons believe about family?”, n.d.). There are now approximately 14 million people who have become members of his church (“Who are the Mormons?”, n.d.).

One of the central ideas behind the Mormon (another name for the religion based on their belief in the Book of Mormon) Church is the idea of family. According to their religion, “family is central to God’s plan.” On September 23, 1995, the president of the religion at the time, Gordon B. Hinckley, shared a statement called “The Family: A Proclamation to the World.” This statement came from the First Presidency and the Quorum of the Twelve Apostle. Below is an excerpt from this statement regarding the obligation of family in the church:

In the premortal realm, spirit sons and daughters knew and worshipped God as their Eternal Father and accepted His plan by which His children could obtain a physical body and gain earthly experience to progress toward perfection and ultimately realize their divine destiny as heirs of eternal life. The divine plan of happiness enables family relationships to be perpetuated beyond the grave. Sacred ordinances and covenants available in holy temples make it possible for individuals to return to the presence of God and for families to be united eternally.

The First Commandment that God gave to Adam and Eve pertained to their potential for parenthood as husband and wife. We declare that God’s commandment for His children to multiply and replenish the earth remains in force (Hinckley, 1995).

This quote reiterates the value of family in the Mormon Church. Below is another quote illustrating that the Mormon idea of family does not stop when life ceases. This quote was taken from the book *Doctrine and Covenants*:

But death does not need to be the end of our relationships with cherished loved ones. The Lord revealed to the Prophet Joseph Smith that the “same sociality which exists among us here will exist among us there [in eternity], only it will be coupled with eternal glory”. Family members who accept the Atonement of Jesus Christ and follow His example can be together forever through sacred ordinances performed in God’s holy temples (Doctrine and Covenants 120:2).

As one can easily see, the ideas of family and procreation are extremely important. Because of this strong value, certain treatments that may interfere with one's ability to procreate are often refused.

In 1982, a study was done wherein chemotherapy drugs were injected into healthy mice. The chemotherapy drugs were proven to disrupt spermatogenesis (Meistrich, Finch, Cunha, Hacker, & Au, 1982). Today, there are techniques such as sperm cryopreservation, the freezing of sperm cells while undergoing chemotherapy to prevent sterility, but even these costly techniques are not one hundred percent effective every time. There is also risk of freezing malignant tissue with spermatocytes, which could lead to risk when these cells are transplanted back into the host (Dolmans, Luyckx, Donnez, Andersen, & Greve, 2013). As a result, Mormons may refuse chemotherapy treatment even though it may be the best option for treating a cancer.

On May 20, 2003, Parker Jensen was treated for Ewing's Sarcoma at Primary Children's Medical Center in Salt Lake City, Utah. Several follow-up tests and scans were performed; however, Ewing's sarcoma can metastasize and may not always show up on these scans. Despite this, the doctors were convinced that this was what Parker had. On May 21, Dr. Wagner, a pediatric oncologist at the hospital talked with the family about Parker's care. With Ewing's sarcoma, it is common to not only excise the local tumor, but also perform adjuvant chemotherapy. This is to ensure that cancer cells that could have metastasized and may have been absent on the scan may be eradicated (Aster, Abbas, Robbins, & Kumar, 2013).

Dr. Wagner explained that the cure rate with the adjuvant chemotherapy would be about sixty to seventy percent, but without the adjuvant chemotherapy it could be as low as twenty percent. Despite this astounding statistic, the Jensen's refused the adjuvant chemotherapy. They thought that because the cancer was not showing up on the scans that it was not really there or could not possibly be Ewing's sarcoma. Instead they preferred to pursue insulin potentiation therapy (IPT), an ineffective treatment as determined by Dr. Wagner.

On June 9, the Jensen's refused chemotherapy, choosing instead to treat Parker with the IPT, and "firing" Primary Children's Hospital saying that they would find another hospital that would provide IPT for Parker. Dr. Wagner then informed the Division of Child and Family Services, which brought the case to court. The case was assigned to a Ms. Cunningham who alleged that the Jensen family was being medically negligent in refusing chemotherapy. Mrs. Jensen continued to take her son to see multiple doctors, including Dr. John Thompson at the LDS Hospital in Salt Lake City, who all agreed with Dr. Wagner that chemotherapy was the best option.

The court ruled that Parker needed chemotherapy, but the Jensen family refused. They fled to Idaho with Parker to prevent Parker from being placed in the custody of the Division of Child and Family Services. The Division of Child and Family Services ultimately accepted that the Jensen family was never going to submit to chemotherapy and that it would be unreasonable to force a now-13-year-old boy to undergo chemotherapy (Jensen v. Cunningham et al, 2011).

Autonomy ultimately triumphed in this situation. Parker did not have to succumb to the adjuvant chemotherapy that doctors adamantly recommended. Doctors exerted

their beneficence in many instances in this case. They fought for Parker, bringing the case to court when Parker's parents refused the adjuvant chemotherapy. They involved Child and Family Services, hoping to take Parker out of the custody of his parents. But, Child and Family Services could only do so much when the parents took Parker and fled to another state. Because Child and Family Services looks at the child and determines what is going to be in the best interest of the child, they did decide that it would be better not to force Parker to go through with chemotherapy. Beneficence did not win in this case, but this is fairly uncommon in pediatric cases as will be demonstrated in some of the following cases.

### *The Hmong Culture*

The Hmong culture is a small southeastern Asian minority group. The Hmong people started arriving in the United States after the Vietnam War; however, their presence in the United States has caused multiple issues because of their unique cultural values, especially in medicine. The men hold the power in this culture. The mother typically converses with the healthcare provider, but the father makes the final decisions (Carteret, 2012).

In addition to the father and the mother, the clan leader and the religious leader play a role in the healthcare of a child. The religious leader is called a shaman, and he usually makes decisions regarding spiritual healing. Spiritual health is a major aspect of health in the Hmong culture. If a Hmong member falls ill to an illness, the shaman usually steps in to help with the healing process, prescribing dietary supplements and sometimes the sacrifice of animals. These illnesses are not necessarily treated with pills

and medical procedures. This can lead to conflict between Hmong families and the medical establishment who may feel that these families are being medically negligent.

An example of this is the story of Lia Lee, a three-month-old Hmong baby with severe epilepsy. The book *The Spirit Catches You and You Fall Down*, written by Anne Fadiman, traces the life of Lia Lee and the family's way of treatment. In the beginning, her parents acquiesced to tests and treatments for their daughter. However, as time progressed and Lia had even more seizures, a cultural barrier was being built. Her parents believed their daughter had *quag dab peg* literally translated as "the spirit catches you and you fall down." They believed a spirit was causing the horrific seizures. They decided that a *txiv neeb* otherwise known as a Hmong healer needed to be the one in charge of Lia's treatment. As a result, the parents would stop her medicine and give her dietary supplements as well as performing sacrifices and chants to keep the spirit away.

Lia's doctors in Western medicine believed that her parents were being negligent in refusing to give her the medication she needed. Through a convoluted series of events, they removed Lia from her parents' care because of their negligence, but she was ultimately returned to them when they agreed to follow the prescribed treatment. However, they still adamantly performed their cultural healing rituals (Fadiman, 2012).

Lia lived for many years ultimately in a vegetative state, and she died at the age of thirty. Unlike the previous case with Parker Jensen, the doctors insisted that Lia's parents follow their orders. Therefore, it was the doctor's beneficence that overruled Lia's parents' autonomy in this situation. However, Lia's parents did not completely lose their entire autonomy. Although they did respect the doctors' orders to follow traditional



Western medical practices, this did not limit their simultaneous usage of their own rituals and practices to heal Lia.

### *The Roman Catholic Church*

The Roman Catholic Church can be traced back to time of Jesus' life and is one of the largest religions of the world. They believe that the Bible holds the truth and is a sacred scripture ("Beliefs and Practices", n.d.).

Life is sacred to the Catholic people. The most obvious issue is the issue of abortion. Catholic doctrine holds that life starts at conception, and that abortion is wrong (Fairchild, n.d.). This value of life continues on to the other extreme of end-of-life-care. The Roman Catholics believe strongly in non-maleficence. Below is a segment from the "Ethical and Religious Directives for Catholic Health Care Services" demonstrating their view of life:

The truth that life is a precious gift from God has profound implications for the question of stewardship over human life. We are not the owners of our lives and, hence, do not have absolute power over life. We have a duty to preserve our life and to use it for the glory of God, but the duty to preserve life is not absolute, for we may reject life-prolonging procedures that are insufficiently beneficial or excessively burdensome.

Because of their view on not prolonging life, they also believe that it is acceptable to refuse treatment. Here is another statement from the "Ethical and Religious Directives for Catholic Health Care Services" permitting Roman Catholics to refuse treatment that they believe wrongly prolongs life:

A person may forgo extraordinary or disproportionate means of preserving life. Disproportionate means are those that in the patient's judgment do not offer a reasonable hope of benefit or entail an excessive burden, or impose excessive expense on the family or the community ("Religious Directives", 2009).

Although most Catholics do not believe in prolonging life through extraordinary measures, there are some members who take the idea of life and family to the extreme and do everything they possibly can to keep their loved one alive.

For example, Emilio Gonzales was a 17-month old baby from Texas who was born with severe medical issues. Emilio was born with Leigh's disease, a progressive condition of the nervous system that is terminal. He was admitted to the hospital on December 28, 2006 and was put on a ventilator and needed a nasogastric tube. The ventilator is an example of a device that many people, including Catholics, would consider an extraordinary measure of keeping a person alive. In this case, doctors believed that Emilio needed to be removed from the ventilator, as it was no longer of any benefit to him. However, Catarina Gonzales, Emilio's mother, refused to let the doctors take Emilio off of the ventilator.

This conflict was referred to the Ethics Committee at the Dell Children's Hospital where they determined that Emilio could be removed from the ventilator if not taken to another hospital or long-term care facility within ten days (Gonzales v. Seton Family of Hospitals et al, 2007). This is consistent with Texas "futile-care" contained in the Texas Advanced Directives Act. It states, "A physician may refuse to honor a patient's advance directive or decision to continue life-sustaining treatment if the physician believes the continued treatment would be medically hopeless or futile" (Marietta 2007). If alternative care is not found within that time, the life-sustaining measures may be removed, which, in this case, would cause Emilio to die.

Catarina argued that her son was responsive to her and still benefitted from life-sustaining measures but the decision was final, and she would need to find a place for

Emilio to go if she wanted him to remain on a ventilator (Gonzales v. Seton Family of Hospitals et al, 2007). Catarina obtained a court order requesting more time to find a location for Emilio; however, Emilio died before another facility could be found (Truog 2007).

Even though Emilio died before another facility was found, it is evident that beneficence prevailed over autonomy. The doctors and executive hospital staff used the TADA to enforce their view of beneficence on the behalf of Emilio. They believed that he could not improve, and therefore, needed to be taken off of the ventilator. Because of this, Catarina was forced to look for other places for Emilio that would keep him on a ventilator. She then exerted her autonomy, battling the hospitals and medical staff to keep Emilio from having to go. She obtained a court order to give herself more time to find a place for Emilio, but he died before this happened anyway. Regardless, this step only would have stalled the process. Emilio still would have had to be moved to another facility due to the “futile-care” law. The case of Emilio Gonzales demonstrates that although the Roman Catholic religion believes that life should not be prolonged, some members such as Catarina Gonzales will disregard this to keep family members alive.

### *Jehovah's Witness*

Jehovah's Witness is a religion that developed in the nineteenth century. The religion was founded by Charles Taze Russell, a Bible student who lived near Pittsburgh, Pennsylvania. He and a group of Bible students began to compare the doctrines of others churches with what the Bible teaches. Their findings were published in a journal called *The Watchtower—Announcing Jehovah's Kingdom* (“Who Was the Founder of Jehovah's Witnesses?”, n.d.).

The Jehovah’s Witness view life, like so many other religions, as extremely sacred. They believe in living lives that are pure in all aspects, spiritually, morally, mentally, and physically. One major issue for Jehovah’s Witnesses is the issue of blood. They believe that “consumption” of blood is unclean in any manner. In a literal sense, it means they will only eat meat if the animal has been properly bled, but in addition, they believe that blood coming from the body should be destroyed. This means that any removal and storage of their own blood or any other person’s blood is unacceptable (“Jehovah’s Witness ethics”, 2009).

In the medical field, it is often difficult to treat a patient that is a Jehovah’s Witness. For a typical patient, if a patient requires blood, it is usually not a moral issue to perform a blood transfusion. However, this is unacceptable for a Jehovah’s Witness. If the patient is competent, a doctor must adhere to his or her wishes.

There are some cases in which blood is acceptable. Below is a table illustrating the acceptable and unacceptable cases (Milligan & Bellamy, 2004):

**Table 3.1: Acceptability of Blood Products and Transfusion-Related Procedures in Jehovah’s Witnesses**

<b>Unacceptable</b>	<b>Acceptable</b>	<b>May Be Acceptable</b>
Whole blood	Cardiopulmonary bypass	Platelets
Packed red blood cells	Renal Dialysis	Clotting factors
Plasma	Acute hypovolemic hemodilution	Albumin
Autologous pre-donation	Recombinant erythropoietin	Immunoglobulins
	Recombinant factor VIIa	Epidural blood patch
		Cell saver

Although it is acceptable for a competent adult to refuse blood, parents of children who are Jehovah’s Witnesses may not be allowed to refuse blood transfusions for a child in dire need of one. This may cause significant conflict, as Jehovah’s Witnesses believe that a person who has received blood from someone else is unclean and unholy.

For example, eight-year-old Elisha McCauley was diagnosed with leukemia on July 19, 1989 when her parents brought her to Leonard Morse Hospital in Massachusetts. Her hematocrit was 14.5% (normal is 40% for a young child). In order for the doctors to confirm the diagnosis and also determine what type of leukemia, they needed to perform a bone marrow aspiration. However, the doctors first wanted to elevate her hematocrit level via transfusion.

However, because the family was Jehovah's Witness, the parents refused the blood transfusion. On July 26, 1989, the judge determined that Elisha needed the transfusion. This meant providing all care including administering blood products. The case also stated that although there is a fundamental right to freedom of religion including religious upbringing of children, these fundamental principles "do not warrant the view that parents have an absolute right to refuse medical treatment for their children on religious grounds." In this case, the judge ruled that without chemotherapy and blood transfusions Elisha would die. Therefore, Elisha was required to receive these substances (In the Matter of Elisha McCauley, 1989).

Similar to Emilio and Parker, the doctors in this case acted out of beneficence, and beneficence prevailed. Elisha's parents had to capitulate in Elisha's treatment plan. This case, however, is unique in that she is now deemed "unholy", because Elisha was required to receive these blood products. Although the doctors pursued what they believed to be best for Elisha medically, she is now no longer looked upon as "unclean" in the faith. However, both the judge and the doctors deemed that Elisha needed these blood products to live. Therefore, the autonomy of the parents had to be disregarded.

## *Conclusion*

Treating cases in pediatric end-of-life care is not an easy task for medical staff. It becomes even more difficult when the family belongs to a culture or religion that interferes with standard Western medical practice. Relational autonomy was discussed in depth in Chapter Two. Relational autonomy focuses on parents and doctors working together to treat a child in the best possible way. The parents make most of the decisions, but doctors can interject if they disagree. In the cases discussed in this chapter, relational autonomy was almost absent, and all of the cases ended up in court.

In pediatric end-of-life care parents and medical staff work together to the best of their ability to find the best treatment for the child. Doctors advocate for the patient and act according to the Hippocratic oath, practicing beneficence in all cases, even if this means taking parents to court for the safety and health of the child. However, parents also try to advocate for their children, as there is more to pediatric care than just medical treatment. Understanding the social implications of pediatric care is just as important as the medical treatment. The next chapter analyzes ways that parents can advocate for their children to provide the best possible care for them.

## CHAPTER FOUR

### The Importance of Advocacy and How It Relates to Relational Autonomy

#### *How Can Parents and Medical Staff Work Together to Meet the Needs of a Child?*

##### *Introduction*

As stated in previous chapters, autonomy is extremely important in medicine, especially pediatric medicine. Children are vulnerable and incompetent in making decisions for themselves and must rely on their parents to make decisions that will benefit them. This is the act of advocating for a child. Although the medical professional may know more about the medical side of a child, in most cases the parents know more about their child's basic needs. Parents are with their children all the time, observing and caring for them. Sometimes they will know better how their child reacts to certain circumstances or his or her needs. This chapter will discuss the importance of advocacy from parents and how a program called Touchpoints is helping to better the relationship between parents and professionals when caring for the parent's sick child.

##### *The Importance of Parents Advocating for Their Child*

Dealing with a sick child can be extremely taxing on a family, particularly parents. Not only is this time stressful due to the nature of dealing with a sick child, it can be difficult for parents to trust the medical staff with their child. However, due to the vulnerability of the child, it is crucial that parents advocate for their children so that the children receive the best possible care. Dennis C. Harper, a professor of pediatrics and rehabilitation at the University of Iowa College of Medicine discusses the hardship in

dealing with a child with a chronic illness in an article published in the *New York Times* (Epstein 2001):

All of these children need a lot of extra work, and typically the mothers get the brunt of it, and sometimes they resent it. It's common to feel angry and then guilty for feeling that way. I think one of the biggest issues is the ambivalence around the future and not being able to predict very well.

It is certainly scary for these parents, and in particular mothers, to watch their child go through the uncertainty of a chronic illness. But, this is where relational autonomy comes into play. If the parents stand back and let the medical professional take over, the medical professional is exerting what he or she feels is the most beneficent option, but it may not be what is actually best for the child in the long run. It takes parents and medical staff working together as a team to find the right treatment plans for a child.

Amy Smith, a Certified Child Life Specialist at Medical City Children's Hospital, talks about ways that parents can advocate for their children when they are in the hospital. First she addresses stressors in the hospital setting and ways to minimize them. Listed below are tables addressing about the various stressors for children in a hospital and ways the medical staff and parents can minimize the stress and anxiety that go along with them:

**Table 4.1: Stressors in the Environment**

Stressors	Minimizing Stress
<ul style="list-style-type: none"> <li>• Medical equipment</li> <li>• Limited mobility and freedom</li> <li>• Confined space</li> <li>• Unfamiliar surroundings</li> <li>• Lack of choice</li> <li>• Frequent disruptions</li> <li>• Lack of control</li> </ul>	<ul style="list-style-type: none"> <li>• Providing age appropriate explanations and opportunities for medical play</li> <li>• Bring favorite comfort items from home</li> <li>• Encourage play</li> <li>• Provide realistic choices when possible</li> <li>• Advocate for care to be done together when possible</li> </ul>



**Table 4.2: Stressors Due to Unfamiliar and Multiple Caregivers**

<b>Stressors</b>	<b>Minimizing Stress</b>
<ul style="list-style-type: none"> <li>• Stranger anxiety</li> <li>• Multiple caregivers and/or seen by multiple medical professionals at once</li> <li>• Separation anxiety</li> <li>• Inconsistency of care-giving techniques</li> </ul>	<ul style="list-style-type: none"> <li>• Limit caregivers and visitors when possible</li> <li>• Is primary nursing and option?</li> <li>• Encourage staff to introduce themselves to your child and get down at their eye level</li> <li>• Provide staff with examples of helpful techniques with your child</li> </ul>

**Table 4.3: Stressors Due to Inconsistency of Routine**

<b>Stressors</b>	<b>Minimizing Stress</b>
<ul style="list-style-type: none"> <li>• Changes in habits from home</li> <li>• Interrupted sleep</li> <li>• Tests and procedures interrupt schedule</li> <li>• Unpredictability</li> </ul>	<ul style="list-style-type: none"> <li>• Develop or modify a routine for hospital visits</li> <li>• Signs posted “I’m asleep, if possible come back later”</li> </ul>

Below is a table of stresses that caregivers face when dealing with a chronically ill child:

**Table 4.4: Stress/Anxiety of Caregivers**

<b>Stressors</b>	<b>Minimizing Stress</b>
<ul style="list-style-type: none"> <li>• Balancing two lives – home and hospital</li> <li>• Concerned for siblings</li> <li>• Various emotions</li> <li>• Family responsibilities</li> </ul>	<ul style="list-style-type: none"> <li>• Accept help when offered</li> <li>• Have one contact person for updates</li> <li>• Delegate responsibilities when you can</li> <li>• Take breaks, ask for a volunteer to stay with your child</li> <li>• Have date night with your spouse or friends</li> </ul>

These tables illustrate the enormity of concerns that cause stress to the patient and to the caregivers, the parents (Advocating for Your Child in the Hospital, n.d.). It is critical that parents and doctors have a close relationship and communicate their thoughts with one another. It is also important that medical professionals recognize these stressors so that

they can manage clinical situations with care, knowing how difficult it is for both parent and child.

One family dealt with these issues and shared their story in blog form. Brad and Amber Bowers have an older daughter, Audrey, and two little boys, Liam and Ben. They also had a son named Luke, but he is now deceased. Audrey and Luke were both born with Smith-Lemli-Opitz syndrome, an autosomal recessive disease where cholesterol is not processed correctly. In one of her blogs, *Loving Lukey*, she describes her journey with Luke during his short five months. One situation, described below, demonstrates one of the reasons communication between the medical professionals and parents is so vital to the comfort and care of the child:

Later yesterday evening your breathing was labored, your CO<sub>2</sub> levels high, although your O<sub>2</sub> levels were good. They called Daddy after intubating you, and we were upset. Just like with Audrey, it was a difficult intubation, took several tries, you were awake for it all. After Audrey's experience, just touching the area around her mouth would cause her to vomit. I was/am afraid you will acquire the same oral aversion. More than anything I was just frustrated, mainly because I could have prevented that from happening. I could have told them you would be difficult, I could have insisted on stronger sedation, I could have warned them ENT needed to intubate and have a scope handy and that the tube size necessary would be smaller than they think. I could have told them all of that if they had given me a heads up. The intubation wasn't urgent and they had time to call me. I understand they aren't used to working with parents who are more aware about the patient's situation than they are, but this is one of those cases. Aggravated, Daddy and I decided to go up there to stress the importance of checking with us before doing anything other than things as mundane as diaper changes or urgent as resuscitation (Bowers, 2012).

In this situation, lack of communication caused hurt and discomfort for the child and stress on the parents. This is why relational autonomy is so important. Relational autonomy stresses the importance of advocacy for a child with the guidance and direction of medical professionals. In this case, Luke needed to be intubated, but communication

regarding how the procedure should have been done would have created less stress on both the child and the parents.

During Luke's illness, the family experienced many stressors. The Bowers had two other children at home to care for so being at the hospital all the time was not going to be feasible. Balancing life at home while dealing with a child who is also dealing with multiple stressors, including new medical equipment, multiple caregivers, and separation anxiety from parents, leads to many emotions and hardships. Being present to advocate for their child was not always an option but in the situation described above, there was time for communication regarding intubation. Amber could have advocated for her child had she been given a chance.

Sometimes, medical professionals do feel like they should be in charge because of their wealth of knowledge in medicine. They may feel like advice from the parent is pointless, because they know what needs to be done medically. However, it is important that medical professionals listen and even encourage parents to speak up, especially if they know something about their child that could change the way a procedure is handled. Parents do know their children best, and it is important that medical professionals remember this when dealing with families.

Because of the belief that a doctor knows best, there may be parents that shy away and do not advocate for their children. In these cases, the doctor has the authority, even if it may not be what is best for the child. The next section will discuss a model developed by a famous pediatrician, which helps medical professionals as well as other people in authority work together with parents to create the best possible outcome for their children.

### *Touchpoints Model*

The Touchpoints model, developed by T. Berry Brazelton, was created to improve the relationships of caregivers (the professionals) and parents (Brazelton & Greenspan, 2000). There are two parts to this model: the developmental model and the relational model. The developmental model focuses on touchpoints in a child's life. Below is a description of what touchpoints are and why they are important in this model:

Touchpoints themselves are the predictable times and events in development at which a child's behavior seems to fall apart. They typically precede a spurt in a particular line of development. And, they are often accompanied by parental frustration and self-doubt. For us, health, education, and social service practitioners concerned with the health and well being of the child and family, these touchpoints can be seen as points of change for the child and the parent as well as for the family as a whole. As such, they offer us the opportunity to make a difference in the lives of young children and their families. Through forming an alliance with parents on behalf of their child we can use these touchpoints as a conceptual framework for behavioral and developmental intervention in well-child care.

This table describes the twelve major touchpoints in a child's life:

**Table 4.5: Touchpoints**

<b>Touchpoint</b>	<b>Themes at Each Touchpoint</b>
Pregnancy	Preparation, imagined babies, relationships, imagined parent
Newborn	Health, parental emotions, the real baby, attachment
3 Weeks	Parental exhaustion, feeding, individuality, relationships
6-8 Weeks	Sociability, parental self-confidence, relationships
4 Months	Attachment, interest in the world, patterns of care, baby's demands, father engagement
7 Months	Motor abilities, feeding, sleeping, objective permanence
9 Months	Mobility, social referencing, person permanence, control
12 Months	Interdependence, motor skills, learning, irritability
15 Months	Autonomy, play, motor skills, dependence,

	language
18 Months	Cognition, sense of self, battles for control, language
2 Years	Pretend play, language, autonomy, motor skills
3 Years	Imagination, fears and phobias, language, peer relations, social understanding

Touchpoints are important even when dealing with a child with a chronic illness. Little things like potty training, eating well, and getting enough sleep can interfere with the child’s ability to cope with an illness. In addition, these touchpoints are critical for parents to understand if they are going to effectively advocate for their children. Below is a list describing the guiding principles in this model:

**Figure 4.1: Touchpoints Guiding Principles**

<p><b>Touchpoints Guiding Principles</b></p> <ol style="list-style-type: none"> <li>1. Value and understand the relationship between you and the parent</li> <li>2. Use the behavior of the child as your language</li> <li>3. Recognize what you bring to the interaction</li> <li>4. Be willing to discuss matters that go beyond your traditional role</li> <li>5. Look for opportunities to support parental mastery</li> <li>6. Focus on the parent-child relationship</li> <li>7. Value passion wherever you find it</li> <li>8. Value disorganization and vulnerability as an opportunity</li> </ol>
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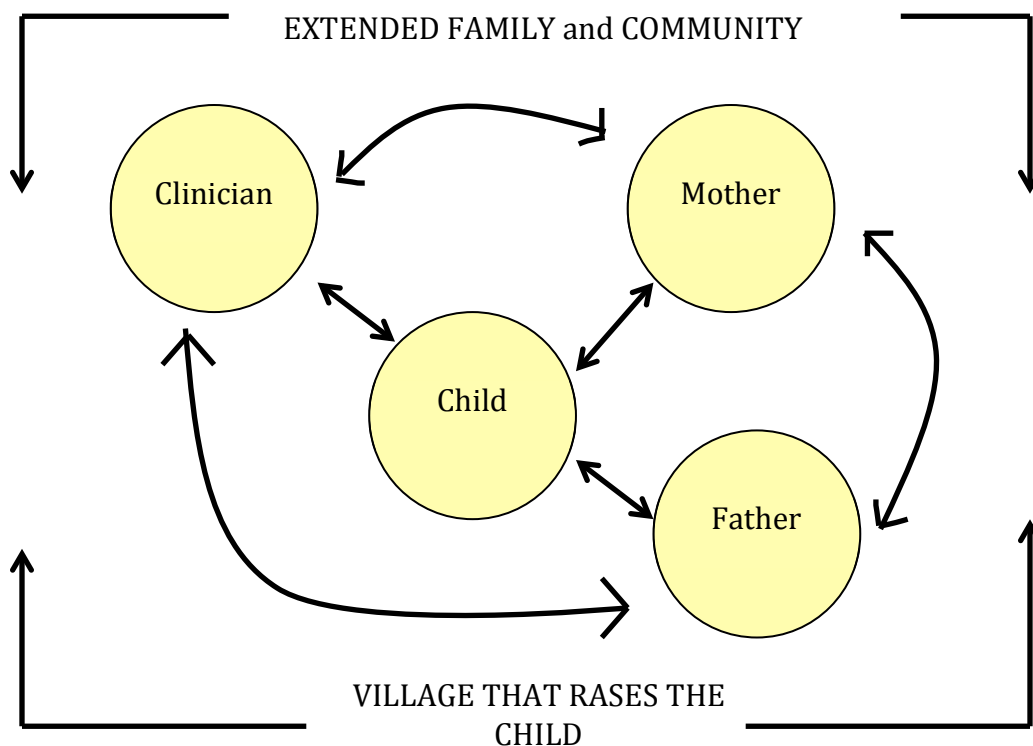
Although the Touchpoints model has two parts, this thesis will focus on the relational model and how it correlates to the idea of relational autonomy. The following is a description of the model from a handbook on the Touchpoints model (Hornstein, 2000):

The relational model describes the alliance that the provider establishes with the child’s parent(s). Elements of this model, which is seen as complementary to the provision of health care and early education, include emphasis on the importance of the relationship between the practitioner and the parent, valuing both the positive and negative passion of the parent, focus on the parent-child relationship, reading one’s own feelings during practitioner-parent interactions, and using the

language of the baby's behavior as a means to establish an authentic connection with the parent.

The idea of relational autonomy fits perfectly with this model. When a medical professional is treating a pediatric patient there are essentially three parties: the medical professional, the parent, and the child. The only way that the child will receive the best possible care is if there is a strong physician-parent relationship. The idea behind the relational model is to teach medical professionals (and other professionals dealing with children) how to build a strong relationship with the parents. Figure 4.2 helps to illustrate the relationships between the parents, the child, the medical professional, and the extended family and friends that also play a role in the treatment process. Communication and effort from all of the parties involved will make for an effective treatment process.

**Figure 4.2: A Systems Approach to Using Touchpoints with Children and Families**



This figure also emphasizes the virtue of trust in medical practice. Parents must trust that the physician has a child's best interest in mind. Physicians have to trust that parents know the social wellbeing of a child. Pellegrino discusses the virtue of trust in his book *The Virtues in Medical Practice*:

We trust professionals in realms in which they have expertise. We trust them not to use that expertise to exploit our vulnerability for their own interests. We trust them for accurate information, and we trust them to empower and enable us to place their recommendations into the full context of our own hierarchy of values. We also trust them to carry out the procedures in which they are skilled and that we cannot perform for ourselves...Since trust is a permanent feature of human relating, fidelity to trust is an indispensable virtue of the good professional.

The role of the provider in this model is not only essential but also extensive. The medical professional must not only know the developmental and medical needs but also the background of the family and how relationships with families can be maintained. Knowing and practicing the principles described in Chapter One is critical. The goal of the practitioner in this model is to provide a system of care for the child; however, the role varies depending on the family. As described in Chapter Two, some families need more support and guidance than others. For example, the role of a medical provider will differ for a person who is a married, middle class, and career-oriented compared to an adolescent, inner city mother who lives with a boyfriend and his family. But the common thread is that both of these mothers need a medical provider who is empathetic and knowledgeable, who can build a strong relationship to best help the mother's child.

The term the Touchpoints model uses to describe the support system is scaffolding. Just like in a building, these parents need support. The scaffolding of the relationship is the framework upon which it is built. That framework is the knowledge and guidance of the medical professional and the support for the particular family based

upon their background. The provider must begin by getting to know the family before any treatment begins. The key is that medical professionals must decide how much scaffolding is necessary for the parents and child. Like the two mothers described above, the scaffolding differs for each family. The treatment process must be catered to what is necessary for the child. Again, this is also the idea behind relational autonomy. The whole purpose is to work together as a team to provide the best support possible for the child.

One core point in the model is the idea of authenticity. A medical provider certainly has a wealth of knowledge, but he or she also has limitations in that knowledge and expertise. The parent also has a wealth of knowledge about his or her child, but he or she does have limitations, especially when it comes to medical knowledge and expertise. The collaboration of knowledge from the medical provider and the parent can be used together to form a beneficial treatment plan for the child. This quote from T. Berry Brazelton sums up this idea perfectly:

As healthcare and childcare professionals, we are well trained to look for the failures and the defects in the child and parents, but these do not endear us to the families we work with. They sense our search for their failures. If we can change to a model of observing and valuing their successes, as opposed to a top-down, agenda-driven model, we can engage parents in a collaborative rather than a prescriptive relationship. Parents are aware and grateful for such a change. When we focus on their strengths, they are far more likely to share with us their vulnerabilities. Though this paradigm shift is easy for many professionals to endorse, it is more difficult for them to alter their interactions with families accordingly. We are too well trained in our medical search for impairments that we can “fix”, to stop, hold back, acknowledge parents’ expertise, and look for opportunities to support their mastery. As a result of our focus on their problems, we leave parents wary and defensive. When we can join them in a collaborative approach, they let down defenses and become available for a working relationship with us.



By acknowledging that parents also have valuable information to share, the relationship is no longer one-sided but rather cooperation and collaboration between two parties, a key component of relational autonomy.

Brazelton’s quote and the idea of authenticity demonstrates the virtue of prudence and the necessity of a physician to have prudence when practicing medicine. Pellegrino discusses the virtue of prudence in his book *The Virtues of Medical Practice*:

Prudence is a guide to the right way of acting with respect to all the virtues. It provides the capacity or disposition to select the right means and the right balance between means and good ends. It orients us to moral truth, to the moral quality of particular acts and their relationship to the ends of human nature. Prudence itself is shaped by the universal moral guideline that we must seek good and avoid evil. Prudence helps us to discern, at this moment, in this situation, what action, given uncertainties of human cognition, will most closely approximate the right and the good...Clinical judgment is essentially an exercise of prudence, “the right way of acting,” to use Aquinas’ definition of prudence, in a complex situation fraught with uncertainties (Pellegrino, 1993, pp. 85-86)

The behavior of the medical professional when meeting with families is also important. The table below lists some behavioral elements that will help make the relationship with the parent mutual:

**Table 4.6: Behavioral Elements in Establishing Mutuality**

Timing	Match the pace and rhythm of the child and parent
Imitation	Mirror movements, body positions, and facial expressions
Interest	Observe for and follow topics of interest to the parent – refocus on the child when interest varies
Facial Expression	Be aware of your facial expressions as tools for communication
Feedback	Constantly read the behavioral feedback – body position, facial expression – you are receiving about your efforts
Dialogue	Be aware of turn-taking in the amount of talk as well as in what is discussed
Eye Contact	Be aware of the effect of eye contact on the parent

Data Collection	Note which areas of the child’s developments affect the parent as you collect data – revise your focus based upon this feedback
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Overall, the ideas behind the Touchpoints model should be utilized even beyond pediatric medicine. A strong relationship between the physician and parent or physician and patient is vital in medicine. In the case with pediatric patients, sometimes these touchpoints may come during the illness. This adds a whole other level of stress for the parents. A medical provider who utilizes the principles listed in Chapter One and the ideas of the Touchpoints model can help to support the parents through words of encouragement and empathy. Occasionally, the child may not go through a touchpoint because of the illness. This may also cause the parent to panic. As a medical professional, affirming that the process is normal and supporting them in a way that is best for their family is the best possible solution to the problem.

Although it may not be the norm, the Touchpoints model is important for physicians to follow. It teaches physicians how to work with families that may come from various cultures and religions, as discussed in Chapter Three. It provides parents an opportunity to share their knowledge of their child that the medical provider might lack. Finally, it reinforces the idea of relational autonomy, which focuses on the parents as the ultimate decision-makers and the medical provider that helps the parents make the medical decisions necessary for their child. The table below demonstrates the “shifts” when the Touchpoints model is used:

**Table 4.7: The Touchpoints “Shifts”**

<b>From</b>	<b>To</b>
Deficit	Positive
Linear Development	Multidimensional Development

Prescriptive	Collaborative
Objective Involvement	Empathetic Involvement
Strict Discipline Boundaries	Flexible Discipline Boundaries

*Conclusion*

The support and advocacy from parents is crucial in pediatrics. Parents do have a wealth of knowledge about their child. As seen in the blog post from the Bowers, sometimes medical professionals lack knowledge that could be helpful in certain situations. This can end up causing more stress to both the child and the parent.

There are already multiple stressors for both the child and the parents when it comes to having a chronically ill child. For the child, the environment can be frightening with new medical equipment, a new location, and many interruptions and distractions. In addition, new caregivers (medical professionals) and a new routine can cause stress and anxiety in a child. Because of this, certain touchpoints, such as sleeping through the night, may be disrupted.

For the parents, the struggle of balancing life at home and in the hospital can be extremely difficult. If the parents have other children, trying to balance their schedules with the schedule of the chronically ill child can be an issue.

The Touchpoint model helps to educate medical professionals on how to have a strong relationship in order to bring about the best care for the child. This includes the idea of relational autonomy where parents have a say in their child’s treatment plan. By encouraging more professionals to learn and utilize the Touchpoint method, relational autonomy will naturally come when making medical decisions for end-of-life care in pediatric patients.

The Touchpoints model also emphasizes Pellegrino's virtues in medical practice. The idea of authenticity where physicians understand that they have limitations demonstrates the virtue of prudence. Touchpoints also encourages parents and physicians to work together with the idea of the child in mind. The virtue of trust must be incorporated into this practice. Parents must trust that the physician has a child's best interest in mind; but physicians must also trust that parents know the social wellbeing of a child. Although Brazelton does not use these virtues directly in his Touchpoints theory, the ideas behind the theory truly accentuate the virtues Pellegrino writes about in his book *The Virtues in Medical Practice*.

## CHAPTER FIVE

### Conclusion

#### *The Importance of Implementing Relational Autonomy When Making Medical Decisions*

This thesis analyzes the conflict between autonomy and beneficence. Chapter One discusses the four core principles according to Thomas Beauchamp and James Childress. These include autonomy, beneficence, non-maleficence, and justice. Autonomy is a patient's right to determine his or her own medical decisions. In pediatric cases, this principle becomes more complex, because parents ultimately make the decisions for their children. The patient-physician relationship changes in the case of pediatrics, because at a certain age children are incompetent of making decisions. According to Piaget, children under the age of seven do not have the cognitive ability to even help in making decisions with their parents. Children under the age of eighteen are legally not allowed to determine their health care. Although this age varies based on a variety of factors such as maturity of the child, this thesis focuses on children close to the age of seven, when parents have full autonomy.

Beneficence is the doctor's responsibility to perform what is best for the patient. Based on his or her medical expertise, the doctor should formulate a treatment plan for the child. This is where the conflict begins. Parents may believe that they know what is best for their child, and therefore they take the care into their own hands, however

doctors know more about the physicality and treatment of an illness. They may have a treatment plan that the parents do not agree with for a variety of reasons.

Chapter Two introduces one way of handling this conflict through a subdivision of autonomy: relational autonomy. Relational autonomy encourages the parents and the doctors to work as a team through communication and collaboration to determine what is best for the child. This subdivision suggests that the medical staff gives input and assists the family in making the medical decisions, and parents and extended friends and family can express their concerns and desires for treatment.

This chapter compares relational autonomy to another subdivision of autonomy called in-control autonomy. In-control autonomy is a concept wherein parents are fully in charge of making the decisions for their children. In this type of autonomy, doctors and medical staff have little input in the decisions that the parents make for treatment. Unfortunately, parents may know their children best when it comes to their personality and needs, but they do not have the medical expertise to choose what best serves the child more.

Chapter Three focuses on the idea of parents and extended family and their religious or cultural backgrounds. The chapter analyzes cases from four different religions that have strict medical rules. In analyzing each of these cases, most often beneficence prevailed, because these children were minors. The judges ruled in favor of the doctors, forcing the children to go through with the various treatments that the doctors ordered. This chapter clearly demonstrates that pediatric cases defy typical cases, because in pediatrics there is an extra party, the parents, that are added to the patient-physician relationship.

In each of the cases discussed in Chapter Three, the parents were actively involved in advocating for their children, which is what led to the court cases. However, some parents lack the ability to care for their children and make the right decisions for their children. Chapter Four discusses how parents can advocate for their children with the help of medical professionals. A model called Touchpoints helps physicians and other people involved in service work together with parents, allowing them to advocate and do what is best for their child. The child is at the center of the model, and physicians, family, and extended family and friends all focus on doing what is best for the child.

In conclusion, relational autonomy, a subdivision of the core principle of autonomy, can be useful in dealing with pediatric end-of-life care cases. Relational autonomy encourages parents and doctors to communicate and collaborate to determine a beneficial treatment plan for the child. To encourage this process, the Touchpoints model can be a useful tool to empower parents and teach them to advocate for their children. The model is not only useful for parents, but it is also useful for the medical staff as well. The medical staff can utilize the model to better communicate with these advocating parents and to learn how to incorporate the parents' thoughts and ideas into the treatment plan. The Touchpoints model demonstrates some of the virtues of medicine by Pellegrino. Virtues including prudence and integrity are just some of the virtues that the Touchpoints model emphasizes. These virtues complement the core principles also necessary in medical practice. Utilizing the Touchpoints model and relational autonomy in pediatric end-of-life care cases could ultimately lead to better communication among parents and medical staff and could potentially cut down on the conflict between autonomy and beneficence.

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