

PEDIATRIC EUTHANASIA: THE END OF LIFE AS AN END IN ITSELF?

An Undergraduate Research Scholars Thesis

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ABSTRACT

Pediatric Euthanasia: The End of Life as an End in Itself? (May 2013)

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The practice of medicine is rife with ethically challenging situations. Two areas of medicine particularly lend themselves to this type of challenge: (a) pediatrics, which abounds with concerns regarding autonomy and (b) end-of-life care, which must address how to best provide healthcare for a patient nearing death. This thesis will apply principles of deontological ethics to the amalgamation of these two difficult situations – euthanasia in children old enough to understand this type of decision, but perhaps too young to make such a choice without external influence. This topic will be discussed from the perspective of conflicting sources of good will among those most involved in such a situation. The people directly concerned in the case of a child’s potential euthanasia may have different perceived moral duties. Kant asserts, “There is no possibility of thinking of anything at all in the world, or even out of it, which can be regarded as good without qualification, except a good will.” A pediatric patient, his legal guardians, and his physician may have seemingly irreconcilable opinions and motivations. The child may feel like he is a burden to his family and that he has a duty to die. The physician might believe, as does the American Medical Association, that euthanasia violates the natural goals of humanity and will negatively affect the quality of healthcare. Lastly, the parents could feel an obligation to end

the pain and suffering of their child. This thesis will present a model suggesting how to account for these different perspectives, analyze the potential perspectives of each of these parties independently, and discuss whether these motivations stem from good will.

DEDICATION

I would like to dedicate my thesis specifically to the children who attended Camp Okawehna, a camp in Nashville, Tennessee for children with end-stage renal disease, in the summer of 2011. I would like to dedicate it more broadly to any child who has suffered from a chronic illness and who has passed away as a result of withdrawing life-sustaining treatment. As stated by William Wordsworth in 1798, “A simple child, that lightly draws its breath, And feels its life in every limb, What should it know of death?” Children do not deserve to suffer to the point that euthanasia or withdrawal of life-sustaining treatment becomes a consideration. I plan to not only dedicate my thesis to these children, but my entire life as I train to become a qualified and empathic physician.

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CHAPTER I

INTRODUCTION TO PEDIATRIC EUTHANASIA

The practice of medicine is rife with ethically challenging situations. Two areas of medicine particularly lend themselves to this type of challenge: (a) pediatrics, which abounds with concerns regarding consent and autonomy and (b) end-of-life care, which must address how to best provide healthcare for a patient nearing death. This thesis will apply principles of deontological ethics to the amalgamation of these two difficult situations – pediatric euthanasia in children old enough to understand this type of decision, but perhaps too young to make such a choice without external influence from parents and healthcare professionals. This topic will be discussed from the perspective of lack of autonomy as a potential barrier to children’s decision making, the distinction between different solutions to end-of-life desires, and conflicting sources of good will among those most involved in a situation where pediatric euthanasia may be an option.

Deontological ethics embodies a normative ethical theory defined by a focus on a person’s duty to do what is right for its own sake, rather than in anticipation of positive consequences.

Deontological ethics focuses on the idea that the morality of an action is contained in the action itself. Thus, an action could have negative consequences but still be considered ethically acceptable. The main proponent of deontological ethics was the German philosopher Immanuel Kant, who developed three formulations of the categorical imperative. These three formulations assert that the ability to universalize a given action determines its morality, we must treat people as means rather than as ends, and we must conduct ourselves as if we occupy the “universal

kingdom of ends.”¹ Many Kantian ideas are directly applicable to pediatric euthanasia and the euthanasia debate in general.

Kant devotes a considerable portion of his *Grounding for the Metaphysics of Morals* discussing the importance of autonomy to rational beings. In analyzing autonomy as it might apply to the pediatric population, we must consider at what point a human being becomes a person. Perhaps this is achieved when a human being is able to have desires relevant to the situation at hand² or when a human being considers himself to belong to a world of understanding rather than a world of sense.³ Whenever a child reaches this stage, the traditional autonomy-oriented arguments regarding euthanasia come into play^{4,5}. The second chapter of this thesis will address how Kant’s idea of autonomy might change when applied to children and how this affects the issue of consent.

Kant’s idea of ends and means is central to his ethical theory. Kant states, “[E]very rational being exists as an end in himself and not merely as a means to be arbitrarily used by this or that will.”⁶

Kant specifies that he is referring to rational beings, which is consistent with our everyday

¹ Immanuel Kant, *Grounding for the Metaphysics of Morals; with on a Supposed Right to Lie Because of Philanthropic Concerns*, trans. James W. Ellington (Indianapolis: Hackett Publishing, 1993).

² Jonathan Glover, *Causing Death and Saving Lives* (Harmondsworth: Penguin, 1977).

³ Kant, *Grounding for the Metaphysics of Morals; with on a Supposed Right to Lie Because of Philanthropic Concerns*.

⁴ Gert Helgesson Manne Sjöstrand, Stefan Eriksson, and Niklas Juth, “Autonomy-Based Arguments against Physician-Assisted Suicide and Euthanasia: A Critique,” *Medicine, Healthcare, and Philosophy* (2011).

⁵ Jr. Thomas E. Hill, “Self-Regarding Suicide: A Modified Kantian View,” *Suicide and Life-Threatening Behavior* (1991).

⁶ Kant, *Grounding for the Metaphysics of Morals; with on a Supposed Right to Lie Because of Philanthropic Concerns*.

actions. We may treat a tree as a means rather than as an end by building a chair out of it. When we use this chair for our personal use, we are neglecting any potential “desires” that the tree originally held. People are unlikely to use this line of reasoning to argue against making the tree into a chair, since trees are not widely considered to be rational beings. It also seems unlikely that Kant would have a problem with this. Advancing up the scale of rationality, we might consider whether it is ethical to make a chair out of elephant bones. In doing so, we are treating the elephant purely as a means for our personal use. Elephants are generally considered to have desires of some level, but it is certainly debatable whether their status as potentially rational agents rivals that of human beings. Then we come to the child. Is a child a rational being? The average child seems to occupy a tenuous middle ground of rationality; she has higher status than an animal (and by extension, a tree) because of her potential to become a rational adult human, but perhaps lower status than a seasoned adult. Erring on the side of caution, we instinctively grant as much autonomy as possible to children. Where holes exist and it seems impractical to grant children full autonomy, we place responsibility with a purportedly rational being, an adult, through paternalism. In the one country where pediatric euthanasia is legal, the Netherlands, only the child’s parents are capable of initiating the process.

The nature of the catalyst that ends a patient’s life is a sensitive area in medical ethics. For instance, Oregon and Washington are the only states in the United States that have enacted the Death with Dignity Act (in 1994 and 2008, respectively), which permits, within certain guidelines, physician-assisted suicide for state citizens 18 years of age and older. The difference

(or lack thereof⁷) between suicide, physician-assisted suicide, continuous deep sedation, and euthanasia of children may become critical when evaluating the morality of each from a deontological perspective. Kant developed several arguments against suicide and specifically says, “To preserve one’s life is a duty; and, furthermore, everyone has also an immediate inclination to do so.”⁸ However, philosophers have pointed out that physician-assisted suicide and euthanasia might actually be justifiable under Kant’s own philosophy.⁹ Kant was not necessarily able to anticipate the implications of his own position.

A final issue playing a pivotal role in the ethics of pediatric euthanasia from a deontological perspective is the conflicting sources of good will in such a scenario. The people directly involved in the case of a child’s potential euthanasia may have different perceived moral duties. Kant unabashedly asserts, “There is no possibility of thinking of anything at all in the world, or even out of it, which can be regarded as good without qualification, except a *good will*.”¹⁰ A pediatric patient, his legal guardians, and his physician may have seemingly irreconcilable opinions and motivations. The child may feel like he is a burden to his family and that he has a duty to die. The physician might have a professional opposition to taking her patients’ lives. Lastly, the parents could feel an obligation to end the pain and suffering of their child. Each of these people is somehow involved in the process of potentially euthanizing a child. The question arises as to whether these conflicting wills are compatible and whether each person’s opinion

⁷ James Rachels, “Active and Passive Euthanasia,” *New England Journal of Medicine* 292, no. 2 (1975).

⁸ Kant, *Grounding for the Metaphysics of Morals; with on a Supposed Right to Lie Because of Philanthropic Concerns*.

⁹ I. Brassington, “Killing People: What Kant Could Have Said About Suicide and Euthanasia but Did Not,” *Journal of medical ethics* 32, no. 10 (2006).

¹⁰ Kant, *Grounding for the Metaphysics of Morals; with on a Supposed Right to Lie Because of Philanthropic Concerns*.

truly constitutes a *good will*, in addition to whether a good will alone is sufficient as the basis for a fair and ethical decision. This will be discussed in the second and third chapters of this thesis.

The road to legalizing euthanasia in general has many obstacles. Known as the slippery slope argument, some people argue that making euthanasia of any sort legal will give doctors an easy way out of lawsuits. A physician may euthanize patients for a variety of reasons, such as to cover up medical errors or to obtain organs for other patients. Taking the slippery slope argument further, the popular television show *Futurama* depicts a time in the future where “suicide booths” could exist. As portrayed in the show, people can simply enter, deposit a quarter, and choose their method of death. The machine questions, “Please select mode of death: quick and painless or slow and horrible?”¹¹ People argue that if euthanasia is legal, it follows that suicide will become legal. The American Medical Association is also opposed to euthanasia, though for a different reason. The *Code of Medical Ethics: Current Opinions with Annotations* states:

The intentional termination of the life of one human being by another – mercy killing – is contrary to that for which the medical profession stands and is contrary to the policy of the American Medical Association. The cessation of the employment of extraordinary means to prolong the life of a body when there is irrefutable evidence that death is imminent is the decision of the patient and/or his immediate family. The advice and judgment of the physician should be freely available to the patient and/or his immediate family.¹²

The opinion of the American Medical Association is not surprising. Even today, medical students in the United States take the Hippocratic Oath (see **Appendix A**) upon completing medical school, which famously asserts, “First, do no harm.” Although it is questionable whether refusing to euthanize a terminally patient in extreme pain is not doing harm, this statement in the

¹¹ David X. Cohen and Matt Groening, “Futurama,” in *Space Pilot 3000* (Fox Broadcasting Company, 1999).

¹² “Code of Medical Ethics: Current Opinions with Annotations,” ed. American Medical Association (2006).

oath has been used to oppose euthanasia. Conversely, the Netherlands enacted the Groningen Protocol in 2004, which states that physicians can actively end the lives of children under the age of 12, but only parents can initiate the process. The Netherlands is currently the only place in the world where pediatric euthanasia is legal. Should more countries consider legalizing child euthanasia? This thesis will systematically evaluate whether the end of a child's life can be an end in itself.

CHAPTER II

GOOD WILL AND AUTONOMY

Introduction

In 1900, pneumonia and influenza, tuberculosis, and enteritis were the three leading causes of death in the United States, and children under 5 accounted for 40 percent of all deaths from these infections. Today, only pneumonia (in combination with influenza) is among the top 10 causes of death overall or for children.¹³ Children are dying less frequently from curable illnesses or unintentional injuries and more frequently from intentional withdrawal of treatment. Presently, two-thirds of deaths in the pediatric intensive care unit follow withdrawal of life-sustaining treatment.¹⁴ With the increase in deaths from withdrawal of treatment comes the necessity for an analysis of the ethics behind such “treatment.” The present analysis will draw on ideas of Kantian good will and the importance of autonomy, as described previously.

The importance of Kantian good will

The centerpiece of Immanuel Kant’s moral philosophy is the idea of a “good will.” According to Kant, nothing exists that is inherently good except for a good will.¹⁵ By this, Kant means that the effects of a good will are not what make it good. For something to be good without qualification, it must be good in itself, not by virtue of its consequences. Its goodness is not determined by its

¹³ CDC, “Achievements in Public Health, 1900-1999: Control of Infectious Diseases,” *Morbidity and Mortality Weekly Report* 48, no. 29 (1999).

¹⁴ Elaine Meyer, “Improving the Quality of End-of-Life Care in the Pediatric Intensive Care Unit: Parents’ Priorities and Recommendations,” *Pediatrics* 117, no. 3 (2006).

¹⁵ Kant, *Grounding for the Metaphysics of Morals; with on a Supposed Right to Lie Because of Philanthropic Concerns*.

perceived efficacy or uselessness.¹⁶ Consequently, it is never acceptable for us to forfeit our good will. Other characteristics, such as health and happiness, can be surrendered in certain situations according to Kant. The link between good will and duty allows us to analyze good will as it applies to other motivations; we can subsequently determine that it may be practically permissible under Kantian ethics to consider motivations such as happiness, health, empathy, and sympathy prior to good will, as long as this prioritization does not impede on the intrinsic goodness of good will.

In defining good will, Kant draws on the more familiar idea of “duty.” Christine Korsgaard describes duty in addition to two other types of motivations: direct inclination and indirect inclination.¹⁷ Korsgaard explains direct inclination as doing something because it makes one happy and indirect inclination as doing something as a means to an end. Conversely, duty is simply doing the right thing *because it is the right thing*. In this sense, an action done out of duty is motivated by good will. This is echoed in Kant’s assertion, as previously stated, that good will is “good without qualification.”¹⁸ According to Kant, actions only have moral worth if they are done from a feeling of duty.

The definition of good will may leave readers feeling uneasy about their motivations for performing some actions, such as the motivation of achieving happiness. Specifically, I may volunteer at a homeless shelter because it makes me happy to help other people, rather than

¹⁶ Ibid.

¹⁷ Christine M. Korsgaard, *Creating the Kingdom of Ends* (Cambridge: Cambridge University Press, 1996), 55.

¹⁸ Kant, *Grounding for the Metaphysics of Morals; with on a Supposed Right to Lie Because of Philanthropic Concerns*.

because I feel a duty to do so. Kant explicitly says, “Good will constitutes the indispensable condition of being worthy of happiness.” However, Kant also admits that being happy may actually be a duty, to the extent that being unhappy may prevent one from being dutiful in other regards.¹⁹ Despite Kant’s determined statement that good will is good in itself, he seems to acknowledge that other things, such as happiness, may be necessary for good will to flourish. Additionally, health is necessary to an extent. If one’s health degrades to the point of death, good will can obviously no longer exist in that person. Further questions arise regarding validity of non-duty-related motivations. I may volunteer at a homeless shelter because I feel a duty to help those less fortunate than I am, but I also derive happiness from the appreciation of those I am helping in an empathic sense. Thus, empathy and sympathy are further possible motivations for actions.

The relationship of empathy and sympathy to good will is similar to that of happiness. Empathy is considered to be a person’s ability to identify with another person’s emotional state, whereas sympathy consists of feeling pity for someone else’s misfortunes. Helping people is a necessity for Kant, but not one borne by empathic obligation. Kant points out, “Because we want aid ourselves we must act out of duty to aid other people.”²⁰ Korsgaard clarifies by stating that you can feel sympathy while performing an action motivated by duty, but the critical point is that you would still perform the action if you were not motivated by sympathy. If sympathy provides necessary support for the action, your motives are impure.²¹ Again though, it seems that *in practice*, there are ancillary requirements for good will that, while they do not make the good

¹⁹ Ibid.

²⁰ Ibid.

²¹ Korsgaard, *Creating the Kingdom of Ends*, 58-59.

will good per se, are necessary for its continued existence. Good health, heightened empathy or sympathy, and increased happiness may help people realize that their actions are good in themselves.

While Korsgaard addresses in particular the idea that someone might feel happiness or empathy secondary to duty, she does not address how someone might feel *duty* secondary to happiness or empathy. Kant would argue that duty is good in itself while happiness and empathy are not and that duty's intrinsic goodness should make it the primary motivation for action. However, it seems that duty as a secondary motivation, as long as its value is not undermined, could still adhere to Kant's philosophy. Consider again the homeless shelter example. I might begin volunteering at a shelter motivated by the feeling that I am sad and that helping other people will make me happy. After my first experience, I might note that my intuition was correct; volunteering at the homeless shelter makes me happy because I am helping people. I continue volunteering at the shelter on a weekly basis, motivated by the happiness I derive from helping people. Over time, I become more familiar with the conditions faced by those who are homeless and the limited resources available to these people. I start to feel a sense of duty to help these people, not because it makes me happy, but because I simply feel an obligation to do it. In this way, the happiness derived from an activity can lead to a feeling of duty to perform the activity.

The previous examples suggest that we might be able to adopt a looser view of Kantian ethics. While duty as the primary motivation for actions may be the main idea of Kant's normative analysis, we should be more flexible in applied situations. W.D. Ross explains Kant's view as the "more reflective attitude":

The conscientious attitude is one which *involves* the thought either of good or of pleasure for someone else, but it is a *more reflective attitude* than that in which we aim directly at the production of some good or some pleasure for another, since... we stop to think whether in all the circumstances the bringing of that good or pleasure into existence is what is really incumbent upon us...²²

The conscientious attitude described by Ross, which is Kant's view, is inherently more powerful than empathy. This view obligates us to act regardless of whether we are feeling empathy or sympathy for the afflicted party, but still accounts for the importance of these feelings on top of duty. Other influential thinkers have expressed the importance of empathy to the human condition. Michael Slote goes so far as to outline a moral philosophy based on the notion of empathy: actions are morally wrong and contrary to moral obligation if they express an absence of "fully developed empathic concern" for others.²³ Author James Baldwin says, "You think your pain and heartbreak are unprecedented in the history of the world... [but] the things that tormented me most were the very things that connected me with all the people who were alive, or who had ever been alive." Empathy is clearly and important aspect of the human condition.

While the argument presented here does not fully demonstrate that happiness, health, empathy, or sympathy are good in themselves, as is Kantian good will, it does suggest that some recognition should be given to the legs that support the inherent goodness of good will in practice. As such, the importance of happiness, health, empathy, and sympathy will be given some credence in the analysis of Kantian ethics as applied to pediatric euthanasia secondary to, of course, the intrinsic goodness of the good will.

²² W.D. Ross, *The Right and the Good* (Oxford: Clarendon Press, 1930). (emphases added)

²³ Michael Slote, *The Ethics of Care and Empathy* (London: Routledge, 2007).

The importance of autonomy for Kant

Autonomy translates directly to “self-rule.” The concept of autonomy is generally understood to mean that an agent’s “self-rule” is free from the control of other people. Additionally, it implies the absence of personal limitations such as lack of knowledge or, perhaps especially in the case of minors, authoritative influence. Autonomy is a critical concept in medical ethics. Competence judgments are considered to have a “gatekeeping role” in health care.²⁴ When a health care provider or a court of law deems a patient incapable of making his or her own decisions, the patient’s autonomy is transferred to an appropriate, capable, autonomous agent, as will be discussed later in this thesis.

It is difficult to overstate the importance of autonomy to Kantian philosophy. Kant argues that autonomy is “the ground of the dignity of human nature and of every rational creature.” He asserts an ethical maxim based on it: “That action which is compatible with the autonomy of the will is permitted; that which is not compatible is forbidden.” By arguing that autonomy is “the *sole* principle of morals,” Kant underscores its importance.²⁵ The first statement in the American Medical Association’s “Principles of Medical Ethics” is: “A physician shall be dedicated to providing competent medical care, with compassion and respect for human dignity and rights.” If, as Kant states, autonomy is the basis of the dignity of human nature, the importance of respecting patients’ autonomy is clear.

²⁴ Tom Beauchamp; James Childress, *Principles of Biomedical Ethics* (Oxford University Press, 2008).

²⁵ Immanuel Kant, *Grounding for the Metaphysics of Morals; with on a Supposed Right to Lie Because of Philanthropic Concerns*, trans. James W. Ellington (Indianapolis: Hackett Publishing, 1993).

CHAPTER III

KANT AND THE PEDIATRIC SPECTRUM OF INDEPENDENCE

The medical autonomy of children

A central issue to medical decision making in children is whether or not children can possess autonomy, and to what extent they should be allowed to exercise this autonomy if they do indeed possess it. Kant states that autonomy is “the ground of the dignity of human nature and of every rational creature.”²⁶ Kantian good will requires that we treat people in such a way that we are respecting their autonomy. But how can the purported autonomy of a child who is, say, six years of age, be quantified? Because full autonomy allows an individual the right to make her own choices, it is logical that a prerequisite for autonomy is an understanding of the consequences of one’s decisions. This understanding requires rationality and self-awareness. Thus, empirically denoting the requirements for a child’s autonomy in the case of potential euthanasia or withdrawal of life-sustaining treatment must depend on these factors. However, the situation is complicated by the fact that such a decision leads to death, which people of all ages struggle to understand. Combining these requirements for autonomy allows us to tentatively assert that a self-aware child who understands to some extent the varied implications and components of death should be granted a corresponding degree of autonomy throughout the medical decision-making process.

While death is a difficult concept for anyone to understand, particular stages in the understanding of death have been identified and linked to roughly estimated ages. The principles of

²⁶ Kant, *Grounding for the Metaphysics of Morals; with on a Supposed Right to Lie Because of Philanthropic Concerns*.

irreversibility, finality, nonfunctionality, universality, and causality must be integrated for a child to understand death to a reasonable degree. A child's individual background will come into play when determining at what age this understanding takes place. But research has suggested that children understand the ideas of irreversibility and finality around three years of age, universality at five to six years of age, and causality by eight to nine years of age. Some emotional and cognitive manifestations indicating that a child is reaching these milestones might be the development of adult concepts of death, the understanding that death can be personal, and an interest in the physiology and details of death.²⁷ Himmelstein (2004) suggests that children should be involved in the decision-making process as early as six to twelve years of age. But the ability to achieve these milestones is obviously not a direct function of age, as indicated by the large range Himmelstein (2004) suggests. The legal definition of medical competence rests on an individual's capacity to rationally understand the consequences of a given decision.²⁸ Therefore, an empirical model for determining a child's understanding of death (and therefore autonomy) would be useful for gauging the contribution the child should have in the decision-making procedure.

Paternalism and the pediatric spectrum of independence

Where an individual's autonomy is missing, paternalism of some sort usually fills the void. Paternalism has been defined in many ways and tends to have both negative and positive connotations. Paternalism can specifically be defined as one agent taking on some of another agent's autonomy for decision-making purposes. The positive connotation of paternalism

²⁷ Bruce Himmelstein, "Pediatric Palliative Care," *The New England journal of medicine* 350, no. 17 (2004).

²⁸ T Vince and A Petros, "Should Children's Autonomy Be Respected by Telling Them of Their Imminent Death?," *Journal of Medical Ethics* 32, no. 1 (2006).

suggests that the paternalistic agent is acting out of compassion and concern, while the negative connotation of paternalism focuses on motivations of self-interest and an element of condescension. Undoubtedly both types of paternalism exist, and may even coexist in a single paternalistic agent.

Autonomy and paternalism can be simplistically viewed as the two variables on a sort of “spectrum of independence.”²⁹ When decisions have to be made, individual autonomy decreases as paternalism from one or more outside sources increases. In a situation involving medical care for a person at any age, paternalism will be involved on the part of the physician. However, this “spectrum” gets significantly more complicated when the quasi-independence of an informed child is introduced. Presented here is a model of how to account for parental and medical paternalism in light of the child’s relative autonomy.

“The Pediatric Spectrum of Independence,” visualized in **Figure 1**, provides a method for accounting for all sources of decision-making input when life-supporting treatment might be withdrawn from a child. A doctor is allowed some paternalism (indicated by D-Paternalism) because of the knowledge gap between the physician and the child and parent(s). The physician’s medical knowledge puts him in a position where he is justified in making decisions on behalf of his patient. The child and her parents likely do not know, for example, the exact dosage of medications the child needs or which surgical procedure might yield the best result. By subjecting oneself to any kind of medical attention, one is necessarily subscribing to the medical

²⁹ M S Komrad, “A Defence of Medical Paternalism: Maximising Patients’ Autonomy,” *Journal of Medical Ethics* 9, no. 1 (1983).

paternalism inherent in the process of allowing another individual to determine the best way to increase overall health and wellbeing. However, the independence accounted for in the D-Paternalism bar decreases accordingly as the knowledge gap between the physician and the child or parent closes. This narrowing of the gap takes place as the child or parent becomes more aware of the medical situation. As the parent becomes more aware, the D-Paternalism is converted to the parent's justified paternalism, P-Paternalism. If, for example, the parent were also a physician, this would significantly decrease the paternalism allotted to the attending physician. As the child becomes more aware of her situation, the D-Paternalism is converted to pure autonomy of the child.

P-Paternalism is justified based on the assumption that the parent has the child's best interests as a priority. Parents usually have an unquestionable commitment towards the wellbeing of their child. There are often similarities in religious, familial, and cultural beliefs that justify the parents in making surrogate decisions for their child. In spite of this, the parents will understandably sometimes be too emotionally involved to make rational decisions on behalf of the child.³⁰ P-Paternalism must be converted to another party in this case, such as to the physician or another responsible family member. Because it is certainly not always the case that parents have their child's best interest at heart,³¹ the proportion of P-Paternalism on the independence spectrum should be allotted accordingly.

³⁰ Karen Street, "The Decision Making Process Regarding the Withdrawal or Withholding of Potential Life-Saving Treatments in a Children's Hospital," *Journal of medical ethics* 26, no. 5 (2000).

³¹ See example in Julie Gladsjo, "Termination of Life Support after Severe Child Abuse: The Role of a Guardian Ad Litem," *Pediatrics* 113, no. 2 (2004).

The child gains more autonomy with increased knowledge of his condition, increased self-awareness, and understanding of death in general, as described previously. Increased knowledge of his condition will allow for an increase in his autonomy at the expense of D-Paternalism, since this knowledge gap validates the D-Paternalism in the first place. Increased self-awareness and understanding of death detracts from the P-Paternalism, since this knowledge allows the child to engage in decisions based on self-interest and with a more complete knowledge of the consequences. A child's lack of self-awareness justifies a parent's paternalism in many cases. It has been shown that a child's focus on the present and limited reflection on choices make it more likely that a child's values will change over time than the values of an older person.³² But as this self-awareness increases, parental paternalism becomes less justified. A child with this kind of knowledge, independent of age, must be considered an autonomous agent as readily as possible.

This model is evidently simplified with regard to several factors. The P-Paternalism may be split between parents. There may be additional guardians or a guardian ad litem involved as well. The D-Paternalism, in the case of a chronically ill child under consideration for euthanasia or physician-assisted suicide, is likely to be divided among teams of specialists, nursing staff, and other health care providers. Cultural differences will also likely affect the spectrum as it is presented here. A particular culture may emphasize physician input more than autonomy of patients of any age.

³² J. P. Orlowski, M. L. Smith, and J. Van Zwiene, "Pediatric Euthanasia," *Am J Dis Child* 146, no. 12 (1992).

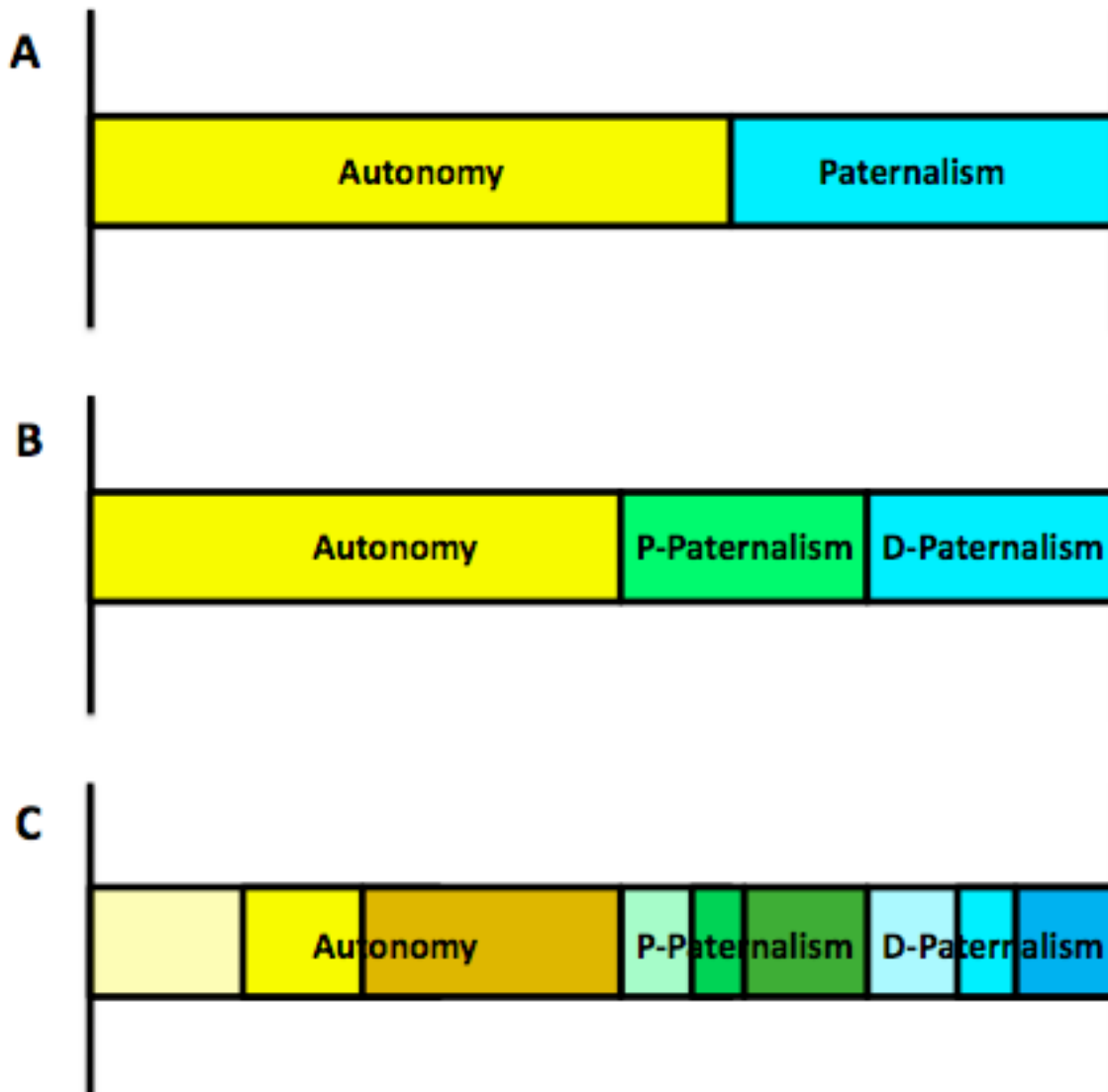


Figure 1. The Pediatric Spectrum of Independence

A.) The first spectrum indicates the distribution of autonomy and paternalism, as will be present in the medical decision-making process for anyone of any age. B.) The middle spectrum shows how parental paternalism enters the picture in a pediatric situation. C.) And finally, the last spectrum shows how individual proportions of autonomy or paternalism can be divided into discrete concerns and can be proportioned based on the intensity of the concern.

Based on this model, an empirical procedure can be developed for decision making. When a decision needs to be made on whether to withdraw life-sustaining treatment of a child, it is critical that each party's opinion is given its due amount of weight during the process. The relative proportion of these weights is determined roughly by the method previously described. The next complication will be the individual concerns of each party. A survey of the literature gives rise to some possible individual concerns in **Table 1**, which is by no means exhaustive. These concerns (and undoubtedly many others, some of which are suggested) may have any degree of importance for a particular case. The relative importance of these factors can be scaled down to fit into the particular proportion that party has been allotted in the spectrum of independence. Ideally, each of these scaled proportions would be labeled as "for" or "against" the decision to withdraw treatment. The decision would be made based on the majority summation of these factors. One important rule that should be universally applied when using the spectrum is that a child's life should never be actively ended against his or her will. While this may seem like common sense, it is also the conclusion required by Kantian ethics. Regardless of how little autonomy a child is left with, if the child has the capability of expressing his wish not to die, he has enough of a decision-making capacity for his wish to be respected. To ignore such a request would be to undermine the autonomy of the child and is consistent neither with Kantian ethics, nor with the aims of the Pediatric Spectrum of Independence.

However, it is challenging to account for all factors involved on the part of each party. It is similarly difficult to quantify the importance of the different factors involved. Ideally, an independent party, such as a hospital ethics committee, would moderate this process to the best of its ability. The variability of human emotions and desires makes it difficult to assign an

empirical model to these kinds of situations. Yet, it will always be useful to isolate important details and determine how they best fit together to come to a decision.

Table 1. Literature survey of individual concerns in the case of pediatric euthanasia

| Child | Parent(s) or Guardian(s) | Doctor(s) |
|--|--|--|
| <ul style="list-style-type: none"> • Loss of autonomy, decreased ability to participate in activities that make life enjoyable, loss of dignity^{33,34} • Loneliness, fear of death^{35,36} • Feeling like a burden on family³⁷ • Feelings of depression and hopelessness³⁸ • Concern for future quality of life³⁹ <p><i>Suggested by author:</i></p> <ul style="list-style-type: none"> • Pain and suffering | <ul style="list-style-type: none"> • Consideration for quality of life, potential for recovery, pain relief, what the child wants or would have wanted⁴⁰ • Spirituality or faith⁴¹ • Pain and suffering of child⁴² <p><i>Suggested by author:</i></p> <ul style="list-style-type: none"> • Child as a strain on financial resources, family cohesion, and parents' time • Stigma associated with having a terminally ill child | <ul style="list-style-type: none"> • Possible legal ramifications⁴³ • Mercy for patient's suffering, professional opposition to taking life⁴⁴ • Consideration for quality of life, potential for recovery, pain relief⁴⁵ • Belief that allowing patients to die negatively affects quality of healthcare⁴⁶ <p><i>Suggested by author:</i></p> <ul style="list-style-type: none"> • Availability of resources • Spirituality or faith |

³³ Richard; David Hopkins Leman, "Sixth Annual Report on Oregon's Death with Dignity Act," ed. Department of Human Services Office of Disease Prevention and Epidemiology (Portland2004).

³⁴ Robert A; Clarissa Hsu; Helene Starks; Anthony L Back; Judith R Gordon; Ashok J Bharucha; Barbara A Koenig; Margaret P Battin Pearlman, "Motivations for Physician-Assisted Suicide," *J Gen Intern Med.* 20, no. 3 (2005).

³⁵ Ibid.

³⁶ Himmelstein, "Pediatric Palliative Care."

³⁷ Hardwig, "Is There a Duty to Die?."

³⁸ W; Rosenfeld Breitbart, BD; Passik, SD, "Interest in Physician-Assisted Suicide among Ambulatory Hiv-Infected Patients," *Am J Psychiatry* 153, no. 2 (1996).

³⁹ Pearlman, "Motivations for Physician-Assisted Suicide."

⁴⁰ Elaine Meyer, "Parental Perspectives on End-of-Life Care in the Pediatric Intensive Care Unit," *Critical care medicine* 30, no. 1 (2002).

⁴¹ "Improving the Quality of End-of-Life Care in the Pediatric Intensive Care Unit: Parents' Priorities and Recommendations."

⁴² Battin, "The Case for Euthanasia."

⁴³ Orlowski, Smith, and Van Zwielen, "Pediatric Euthanasia."

⁴⁴ L Kass, "Neither for Love nor Money: Why Doctors Must Not Kill," *Public Interest* 94(1989).

⁴⁵ J. P. Burns, "End-of-Life Care in the Pediatric Intensive Care Unit: Attitudes and Practices of Pediatric Critical Care Physicians and Nurses," *Critical care medicine* 29, no. 3 (2001).

⁴⁶ Gay-Williams, "The Wrongfulness of Euthanasia."

Analyzing the pediatric spectrum of independence model through Kantian autonomy and good will

Now that a model has been established for decision making in pediatric end-of-life care, we must consider how Kantian ethics impact the model. This analysis will hopefully yield an answer to the question of whether withdrawal of life-sustaining treatment in a terminally ill child can be considered an “end in itself.” For such an action to be considered a Kantian end rather than a means, it is important that the motivations involved stem from the principles important to Kantian ethics. Before conducting this analysis, it is important to examine whether the model itself is “Kantian enough” in nature to be used to make such judgments.

The Pediatric Spectrum of Independence was designed such that autonomy is relegated to the child whenever possible. Autonomy is only taken away from the child when he or she cannot yet be considered a fully rational agent, which is one of Kant’s pre-requisites for autonomy. Any autonomy transferred away from the child has an explicit reason for not belonging to the child and should be transferred back whenever possible. This central focus on autonomy aligns with Kant’s assertion that autonomy is “the sole principle of morals.”

Kant would respond to the relative weights of different motivations in the spectrum based on their adherence to good will or respect for the agent’s autonomy as the primary motivators. Some motivations will stem more from good will or concern for autonomy than others. Good will comes with a sense of duty, and there are instances in which parents, doctors, and even the child will act in self-interest, either selfishly or by imposing their own will on others (perhaps unintentionally). As previously argued, happiness, health, empathy, and sympathy also have a

place in determining the weight of a given motivation in the spectrum, but only secondary to good will. Because Kant does not attempt to tease apart the relative importance of these qualities, it is difficult to say how each of them would affect a motivation's weight in the spectrum according to Kant. It can only be said conclusively that good will is the most important motivator, in addition to respect for the patient's autonomy. In the application of these ideas, it would be best to tailor the relative importance of these factors to individual situations, since they lack the indisputable importance of good will and autonomy. In this analysis, the motivations of the different parties involved in an end-of-life decision gleaned from a survey of the literature will be systematically analyzed. Primary importance will be given to whether the motivation stems from good will and to what extent it considers the autonomy of the patient. Of secondary importance are issues such as happiness, health, empathy, and sympathy as applied to different agents. It is important to remember that this analysis comes from the perspective of Kantian ethics. While some issues may be analyzed in similar ways under a different ethical theory, the perspective offered here is only one of many. A similar analysis conducted under the guiding principles of, for example, utilitarianism, would yield drastically different results.

The most important motivation a child can have for any kind of decision making is the feeling of losing autonomy. Because of the nature of the Pediatric Spectrum of Independence, the child's autonomy has already been limited. A child's feeling that her autonomy is being further reduced by her illness or her situation is of the utmost importance. Kant asserts that autonomy correlates with rationality; a rational being is allowed autonomy. It is important to recognize when autonomy is being diminished for reasons other than changes in rational capacities. For example, a child may not exhibit changes in cognitive ability or decision-making capacity from when she

was completely healthy, but her ailment might prevent her from being able to walk or use the restroom independently. Thus, if the autonomy allotted to her has decreased, this has nothing to do with rationality and would be a valid complaint. A child whose decisions are motivated by decreased ability to participate in activities that make life enjoyable is indirectly experiencing reduced autonomy. Changes in physical abilities that limit overall autonomy are also likely to limit participation in activities in which the child could previously engage. Feeling like a burden on one's family may similarly stem from limited autonomy. As the child's autonomy diminishes due to sickness, it is likely that that surrendered autonomy will be picked up as P-Paternalism. The inability of the child to go to the restroom or participate in enjoyable activities will not be reflected in the doctor's paternalism, since the doctor's paternalism rests only on a discrepancy in medical knowledge. Finally, it is likely that loss of dignity can also be categorized as a type of diminished autonomy. The remaining possible motivations for a child in the given situation are less likely to stem from concerns related to autonomy. Loneliness, fear of death, and feelings of depression and hopelessness concern the happiness of the child and must, according to Kant, fall secondary to autonomy-related concerns. Depending on the psychological effects of these feelings on the child, they could also be classified under health. A child's concern for her future quality of life comes more directly under both happiness and health.

With regard to the physician's perspective in pediatric end-of-life decision making, duty is a complex notion. The physician has at least two discernible sources of Kantian duty: duty from his position as a physician and duty from his position as a fellow rational human being. A physician's purported duties as a doctor are outlined in a variety of codes of ethics, including the Hippocratic Oath (see **Appendix A**) and Beauchamp and Childress's widely used four principles

of biomedical ethics (autonomy, nonmaleficence, beneficence, and justice). A doctor's duties as a physician and as a person will likely overlap, depending on her relationship with the patient and the patient's family. A general practitioner who has taken care of several generations of a family has a better understanding of the family's situation than a specialist who has been caring for a patient for several months.

A variety of concerns can affect how a physician will respond to a patient's request to die. A doctor taking this request seriously will have to consider the possible legal ramifications. If the patient is over 18 and is a legal resident of Oregon, where the Death with Dignity Act was passed, the physician may have the option of physician-assisted suicide. In most other places, a physician actively helping a patient die can suffer severe legal ramifications, as demonstrated by the classic case of Dr. Jack Kavorkian, also known as "Dr. Death," who advocated physician-assisted suicide and famously said, "dying is not a crime."⁴⁷ Dr. Kavorkian's actions of helping over 130 patients die resulted in a conviction for second-degree murder and his serving eight years in prison. Clearly, personal motivations will influence a physician to not illegally help a patient die, since the result would be a prison sentence. But the question remains whether this motivation constitutes an expression of good will. Is a physician's duty more towards the law or his patients? Adherence to the law is not listed anywhere in the Hippocratic Oath (see **Appendix A**), nor is it a point of emphasis for Beauchamp and Childress's four principles of biomedical ethics. The question of whether a physician should break the law in an action that has been agreed by all parties to be in the best interest of the patient is analogous to Socrates' statement in *The Apology* that he would refuse to stop philosophizing if the court were to command it. In

⁴⁷ Samuel Wells, and Ben Quash, *Introducing Christian Ethics*, (John Wiley and Sons, 2010), 329.

Plato's *The Apology* and *Crito*, it can be argued that rather than following the law at all times, Socrates acts on his duty to be loyal to justice. A person might have a duty (perhaps even a Kantian duty) to do what is objectively good, rather than to simply do what the law says. As is demonstrated by a variety of historical examples, the law does not always align with what is objectively good or right. However, another argument can be made in this vein; a person motivated by good will who acts illegally will be imprisoned and will thereby be unable to perform any further actions. It might be argued that proper good will would actually require such a person *not* to perform an incriminating action, which would then lead to his removal from society. This argument has also been presented in Socrates' defense.⁴⁸ The concept of a physician's mercy for her patient's suffering will also be important in considering motivations having to do with legal ramifications.

A doctor may also have a professional opposition to taking life, which commonly stems from the idea that doctors are meant to be healers and preservers of life, not killers. The standing of this concern from a Kantian perspective depends on the basis of the motivation. For example, the physician may believe that allowing patients to die negatively affects the quality of healthcare. This is an outcome-based concern and is not legitimate in the eyes of Kantian ethics. The focus of this motivation is neither on good will, nor on autonomy, since the patient is being treated as a means to an end to better the healthcare system. This would be acceptable under utilitarian ethics, but certainly not under Kantian ethics.

⁴⁸ Holland M. Kaplan, "Socrates: A Lyre in Tune," *The Idea: The Undergraduate Journal of Philosophy at Texas A&M University*, 1, no. 1 (2011): 15-26.

Some other considerations a physician might have in this situation are concern for quality of life, potential for recovery, and pain relief. Taking these things into account as the physician increases the chance that more autonomy will later be able to be transferred back to the child. By increasing her patient's quality of life, the physician makes it more likely that the child will be able to make autonomous decisions sooner. Considering potential for recovery is critical and is an important motivation for decision making on the part of the physician. Kant famously argues that suicide is unethical because it involves using oneself as a means to an end. Additionally, suicide eliminates an agent's autonomy by ending the life of the agent. However, a case can be made that a physician still has a Kantian obligation to inform a pediatric patient of his potential for recovery and (perhaps) offer the patient the option of euthanasia or physician-assisted suicide. Consider an example in which a child is suffering from a terminal illness and is projected to live for only one more week, in which he will continue to suffer immense amounts of pain. Clearly, the child's potential for recovery is bleak and his autonomy is likely at a minimum at this point. For the physician to continue to keep the child alive for any reason other than the request of the child conflicts with Kantian ethics. If the physician prolongs the life of the child, she is prolonging the child's existence in a state of minimal autonomy, which Kant would find undesirable. Secondly, the quality of life of the child is so low at this point that keeping him alive is acting more in the interest of the parents or the doctors than in the interest of the child himself. Especially in this state of minimal autonomy, the interests of the child should be considered whenever possible. It is unethical to treat the child as a means serving the will of any third party. The child must continue to be treated as an end in himself, even if that means hastening his death in bleak circumstances. Focusing on these goals aligns with the physician's duties as a doctor (according to Beauchamp and Childress) and as a person (maximizing

autonomy in the patient and treating her as an autonomous end in herself). However, as stated previously, a child's life should never be taken against the will of the child.

Many of the potential motivations for decision making for parents of a seriously ill child are similar to those already discussed. A parent, like a physician, will be concerned about the child's quality of life, potential for recovery, and pain and suffering. The parent, due to his or her assumedly close connection with the child, will also empathize more strongly with some of the child's feelings. The distinct motivations for parents as reflected in the literature survey of **Table 1** are acting based on what the child wants or would have wanted and the influence of spirituality or faith. Parents' desire to act based on the child's wishes are justified, but with a caveat. In the Pediatric Spectrum of Independence, there is a clear reason that some of the child's autonomy is transferred to P-Paternalism; namely, the child may not understand the concepts associated with death or the child may not understand the consequences of her actions. A parent placing additional, unjustified value on the remaining autonomy of the child is not acting out of good will, because he is neglecting the initial reason he was allotted the child's autonomy in the first place. An example that seems ridiculous, but illustrates this point follows: Perhaps a terminally ill child wants to die because treatments of his illness have caused him to lose all of his hair. Before his illness, his favorite activity was playing with his hair, but he can no longer do this and sees no point in living anymore. It would be ridiculous for the parent to say, "If he sees so much value in playing with his hair and he can no longer do this, he should be allowed to decide to end his life." This line of reasoning is placing way too much value in the child's limited decision-making capacity. The purpose of P-Paternalism in the Pediatric Spectrum of Independence is to

counterbalance these kinds of motivations a child might have for wanting to die in such a situation.

Finally, the parents may consider religion or spirituality in making end-of-life decisions for their child. Perhaps the family practices a religion that holds beliefs that affect the way they can receive health care. The child may or may not be old enough to hold these beliefs herself. This is a difficult situation, as can be illustrated by Jehovah's Witnesses who believe that specific passages in the Bible prohibit them from receiving blood transfusions.⁴⁹ Imagine a case in which a young child's parents are Jehovah's Witnesses. However, the child is too young to understand the beliefs associated with the religion. The child desperately needs a blood transfusion, or he will surely die. The parents do not want the child to get a blood transfusion because of their religious beliefs. Is it ethical for the physicians involved to let the child die because of his parents' religious beliefs? There are several precedents for this type of situation, including a recent case in the United States where a judge ruled that a 4-year-old girl should receive blood transfusions against the wishes of her parents, who were Jehovah's Witnesses.⁵⁰ It is an open question how religious beliefs tie in to parents' expression of good will.

Conclusion

The aim of this thesis has been to determine whether the end of a child's life can be an end in itself, or, more specifically, whether actively or passively ending the life of a child can be justified by deontological ethics. The uniqueness of each case involving a dying child makes it

⁴⁹ *Keep Yourself in God's Love*, (Watch Tower Bible & Tract Society, 2008), 77.

⁵⁰ Silverman, Hannah. News Limited, "News.com.au." Last modified June 1, 2012. Accessed April 2, 2013.

difficult, if not impossible, to make blanket statements about the ethics of such situations. Through examinations of autonomy, good will, and duty, a model was developed that can be applied to end-of-life situations in children: the Pediatric Spectrum of Independence. The Spectrum provides a model healthcare providers can use to frame, articulate, organize, and prioritize the different concerns of parties involved in a variety of situations. While this thesis does not conclude that ending the life of a child is truly an end in itself, through the use of this model it can at least provide a way to determine if this is the case in individual situations.

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APPENDIX A

Below is a modern version of the Hippocratic Oath, written in 1964 by Louis Lasagna, Academic Dean of the School of Medicine at Tufts University, used in many medical schools today, and revised from the classical version to reflect modern medicine.

I swear to fulfill, to the best of my ability and judgment, this covenant:

I will respect the hard-won scientific gains of those physicians in whose steps I walk, and gladly share such knowledge as is mine with those who are to follow.

I will apply, for the benefit of the sick, all measures [that] are required, avoiding those twin traps of overtreatment and therapeutic nihilism.

I will remember that there is art to medicine as well as science, and that warmth, sympathy, and understanding may outweigh the surgeon's knife or the chemist's drug.

I will not be ashamed to say "I know not," nor will I fail to call in my colleagues when the skills of another are needed for a patient's recovery.

I will respect the privacy of my patients, for their problems are not disclosed to me that the world may know. Most especially must I tread with care in matters of life and death. If it is given me to save a life, all thanks. But it may also be within my power to take a life; this awesome responsibility must be faced with great humbleness and awareness of my own frailty. Above all, I must not play at God.

I will remember that I do not treat a fever chart, a cancerous growth, but a sick human being, whose illness may affect the person's family and economic stability. My responsibility includes these related problems, if I am to care adequately for the sick.

I will prevent disease whenever I can, for prevention is preferable to cure.

I will remember that I remain a member of society, with special obligations to all my fellow human beings, those sound of mind and body as well as the infirm.

If I do not violate this oath, may I enjoy life and art, respected while I live and remembered with affection thereafter. May I always act so as to preserve the finest traditions of my calling and may I long experience the joy of healing those who seek my help.