THE INTIMATE CONNECTION BETWEEN AUTONOMY AND DECISION-MAKING IN APPLIED HEALTH CARE ETHICS

-A CASE STUDY IN BEAUCHAMP AND CHILDRESS-

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Autonomy, Decision-Making, Beauchamp and Childress, Case Study, Health Care Ethics.
ABSTRACT

The intimate connection between autonomy and decision-making in applied health care, especially in various kinds of consent and refusal has taken center stage in medical ethics since the Salgo decision in 1957. Prior to that time, the physician’s supposedly moral duty to provide appropriate medical care typically surpassed the legal obligation to respect patient’s autonomy. The Salgo decision concluded that physicians have a legal duty to provide facts necessary for the patient to make an informed decision. "The doctor knows best" long ago was replaced with "The doctor proposes; the patient disposes."
There is no legal obligation for the patient’s choice to be palatable to anyone, other than that patient himself/herself. Although Beauchamp and Childress justified the obligation to solicit decisions from patients and potential research subjects by the principle of respect for autonomy, they however, acknowledged that the principle’s precise demands remain unsettled and open to interpretations and specification. This thesis addresses a current debate in the bioethical community on the four-principle approach. Using Tom Beauchamp and James Childress as case study, to discuss mainly the principle of respect for autonomy, I go on to explain their central arguments concerning this principle in relation to decision making in health care ethics. Rather than focus on their respective weaknesses, which many theorist and health care professionals do, I emphasis instead on the contribution the principle of respect for autonomy can make in the process of ethical decision making in health care situation.
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I thank Tom L. Beauchamp for encouraging me to write on my chosen topic. In the same vain, I am grateful to Raanan Gillon, who not only encouraged me, but also gave me some references that were very instrumental to the actualization of this thesis. Finally, I thank all my friends and colleagues in the programme for all our discussions that might have in one way or the other geared towards making this thesis a success.
DEDICATION

To

The Acton Institute
And
My beloved Parents.

I can no other answer make but thanks,
And thanks, and ever thanks.

Twelfth Night
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GENERAL INTRODUCTION.

The concepts, Liberty, Autonomy and Freedom became prominent during the enlightenment period. Today in health care ethics, following the advancement of biotechnology, questions of liberty, autonomy and freedom are being addressed.

Contemporary biomedical ethics reflects theoretical conflicts of considerable complexity. In complex societies such as those found in North America and Europe patients from diverse ethnic, cultural, and religious backgrounds increasingly confront health care professionals. This affects the relationship between clinicians and patients to the extent that patients' deliberations upon the proposed courses of treatment can, in various ways and to varying extents, be influenced by their ethnic, cultural, and religious commitments.

Although a wide agreement that we can teach and practice biomedical ethics exist, there is, at the same time, divergent opinion regarding the methods for achieving these goals. Some moral philosophers have concerned themselves with constructing frameworks adequate for making informed ethical decisions in situations as they might appear within the healthcare sections of modern society. Tom Beauchamp and James Childress use the term ‘principles’ to designate the most general normative standard of conduct and their set of principles was developed specifically for biomedical ethics and was never presented as a comprehensive ethical theory. According to them, a set of principles in a moral account should function as an analytical framework that expresses the general values underlying rules in the common morality. These principles can then function as guidelines for professional ethics. They defended four cluster of moral principles that serve this function, namely: principle of respect for autonomy; principle of non-maleficence; principle of beneficence and principle of justice. The approach using these principles does not provide a unique solution to dilemmas. One of the common and misguided criticisms of the four principles is that they constitute a deductive system and therefore, presumably, a rigid method for arriving at solutions to complex ethical dilemmas.

Although the principles in their framework are grouped under four general categories, the principle of respect for autonomy is the only one I will discuss at large in this thesis. I
chose to write only on this version because health care professionals traditionally neglected this part of morality among others. Beauchamp and Childress’s structure of principles went beyond this tradition/commitment, by including the principle of respect for autonomy, among other parts of morality that traditionally have been neglected. Since that time, modern American biomedical ethical thought has been widely criticised for its preoccupation with patient autonomy. If there is one concept at the center of the "bioethics movement," it is autonomy. The notion that patients have a moral claim to direct the course of their own medical care and to be given reasonably full information in order to make medical decisions is the most significant challenge of the bioethics movement to conventional medicine. Respect for the autonomous choice of persons runs deep in common morality. There is divergent opinion concerning its nature, scope, or strength. A recurrent complaint about the four principles approach is that although in theory it claims not to prioritise any one of the principles, in practice respect for autonomy recurrently is prioritised. 

The role of the principle of respect for autonomy is better understood in the context of examining individuals’ decision-making in health care, especially informed consent and refusal. Thus informed consent also offers the clearest demonstration of the role of patient autonomy in medicine. The role of this principle has raised variety of questions in applied health care ethics:

What is autonomy? Why should we respect autonomous choices?
Should respect for autonomy mean that a person can request assistance in ending his/her life? Does respect for autonomy mean that a patient can request treatment that the clinician does not think is in his/her best interests, or treatment that is futile? Does it require us to consult them and obtain their consent before we do anything in the bid to help them? Who has the upper hand in decision-making? It is the physician or the patient? What is the intimate connection between autonomy and decision-making, especially when the conflicts and moral dilemmas in specific cases are so deep?

In the first chapter of this thesis, I will deal with a specific aspect of the ‘four-principle-approach’, namely the ‘principle of respect for autonomy’, which I will outline and give a systematic overview on. The product of the systematic overview shall serve as a general perspective on the concept of autonomy. I will set out to define the concept
‘autonomy’. I will give historical development of the concept, tracing it from early Greek political philosophy, where it first appeared and was used to indicate the independence of Greek city-states from outside control, probably from a conqueror, and their determination of their own laws, to contemporary applied ethics. Moving further in this chapter, I will outline three types of autonomy and give a brief definition of them each. Finally in this chapter, I will discuss other relevant concepts and principles. Most importantly, I will discuss the concepts of ‘paternalism’ and ‘informed consent’.

The second chapter begins with Beauchamp and Childress’ development of the four principles. The product of this will give us the idea of the development of the principle of respect for autonomy, because it is in talking about Beauchamp and Childress’ development of the four principles that you can clearly understand their development of the principle of respect for autonomy. This will lead to the discussion on the role of respect for autonomy. This discussion is very relevant, following divergent opinion concerning its nature, scope, or strength. However, since the role of the principle of respect for autonomy is better understood in the context of examining individuals’ decision-making in health care, especially informed consent and refusal, I will move on in this chapter to discuss the intimate relation between autonomy and decision-making in health care ethics. Because this discussion comprises the topic of this thesis, I consider this chapter very relevant and invariably, the most important. While it is true that some writers in bioethics seem to affirm a duty of medical decision-making by patients, Beauchamp and Childress do not. They rather defend a principle of respect for autonomy with a correlative right to choose (not a mandatory duty to choose). Since decision-making for incompetent patients is a troubling ethical problem, I will discuss surrogate decision-making in brief. Finally in this chapter, I will consider the scope of application of the principle of respect for autonomy in general and also in relation to the other three principles in the framework.

Chapter three will throw some light in the scope of application of the principle of respect for autonomy in different cases in health care. Here, I will make reference to three different cases in health care ethics, namely, ‘the standard Jehovah’s Witness case’; ‘the child of a Jehovah’s Witness case’, and ‘Helga Wanglie’s case’. Beauchamp and
Childress share the view that it is legitimate and rewarding to diagnose cases through the lens of general ethical principles.

The fourth chapter ushers in recent critiques of Beauchamp and Childress and reaction to the criticisms. Questions about the adequacy to resolve critical issues in bioethics and in clinical practice through the four-principle approach provoke controversy. Beauchamp and Childress have offered an extended defense of their theory and critical examination of points of debate. The critics that appear in this chapter will include Danner Clouser and Bernard Gert; the Danish physician Henrik R. Wulff; and, R. H. Nicholson.

One of the arguments of Danner Clouser and Bernard Gert, as we shall see, is that the ‘principles’ are not action guides at all, but that at most they represent a category of concerns, a listing of issues that should be considered in dealing with the problem in question. Wulff does not think that one can use Beauchamp and Childress’ bioethical principles as a tool for solving problems in the Nordic context because they do not correspond with the Golden Rule. For Nicholson the four principles might not after all be the last word in medical ethics. However, Beauchamp, Childress and Gillon offer a counter-argument against the arguments that rejected the four principles approach.

Finally in the last chapter, I will make a systematic evaluation of the thesis. This will give a succinct view of the whole work, by running through all the chapters. I will then conclude the work. In my conclusion, I will maintain that the principle of respect for autonomy, together with the other principles do not presuppose a special religious, case, or Metaphysical base. Its interpretation depends on the case, culture, or religion. Which principle weighs the heaviest depends on the culture, case, etc, to which they are applied. I will go on to justify the obligation to solicit decisions from patients and potential research subjects by the principle of respect for autonomy, however, I must also acknowledged that the principle’s precise demands remain unsettled and open to interpretations and specification.
CHAPTER ONE.

1.0. SYSTEMATIC OVERVIEW OF AUTONOMY

1.1. WHAT IS AUTONOMY?

I prefer to begin the work by defining the concept of autonomy literally and in relation to applied health care ethics. This, I believe will enhance a systematic knowledge of the concept.

Etymologically, the concept of autonomy is derived from two Greek words “autos” (self) and “nomos” (rule or law), which literally means self-rule or self-determination. In the field of applied ethics, the term has been used with various technical meanings in different schools of ethics. Almost twenty-six years ago, Gerald Dworkin pointed out that the concept of moral autonomy is defined at least in six substantially different ways in philosophical discourse:

i. A person is morally autonomous if and only if he/she is the author of his/her moral principles, their originator.

ii. A person is morally autonomous if and only if he/she chooses his/her moral principles.

iii. A person is morally autonomous if and only if the ultimate authority or source of his/her moral principles is his/her will.

iv. A person is morally autonomous if and only if he/she decides which moral principles to accept as binding upon him/her.

v. A person is morally autonomous if and only if he/she bears the responsibility for the moral theory he/she accepts and the principles he applies.

vi. A person is morally autonomous if and only if he/she refuses to accept others as moral authorities, that is, he/she does not accept without independent consideration, the judgment of others as to what is morally correct.¹

We can see that the concept of autonomy is open to different interpretations. However, subsequent discussions and study have shown that even these six definitions do not exhaust the field, and that the discussion of the exact content scope and limits of moral autonomy is still open. It is common, precisely in health care ethics, to distinguish autonomy from the principle of respect for autonomy. Gillon made an allusion to this when he said,

> Autonomy must be distinguished from what is often known as the principle of autonomy, and which for clarity would be better known as the principle of respect for autonomy.²

In this thesis, I will try to keep the terms separately.

1.2. HISTORICAL OVERVIEW OF THE CONCEPT OF AUTONOMY.

The concept of autonomy first appeared in early Greek political philosophy. It was used to indicate the independence of Greek city-states from outside control, probably from a conqueror, and their determination of their own laws. Then, autarchy was synonymous to autonomy and was seen as important because it allowed the citizens of an autarchic city-state to promulgate laws, which were especially suitable to their specific situation. Autonomy during this period was always with reference to city-states and not individual persons.

After this period, the concept was in the silence. Not even in the medieval period was it discussed. It was only the renaissance period that shaded light on it again. According to Holm’s report,

> In the medieval period, discussions of autonomy were not prominent either and the concept lay dormant until the enlightenment period, where it was revived and connected to the growing emphasis on individualism in philosophy and in society at large.³

This report shows that, not only was the concept of autonomy revived at the enlightenment period, but also emphases were shifted from Greek city-states to the individual. The concept became central in the influential moral philosophy of Immanuel Kant and John Stuart Mill in the 18th and 19th centuries respectively. They argued that respect for autonomy flows from the recognition that all persons have unconditional worth, each having the capacity to determine his or her own moral destiny. To violate a person’s autonomy is, according to Kant; to treat that person merely as a means, that is, in accordance with others’ without regard to the person’s own goals. Mills was primarily concerned about the “individuality” of autonomous agents. He argued that society should permit individuals to develop according to their convictions, as long as they do not interfere with a like expression of freedom by others; but he also insisted that we sometimes are obliged to seek to persuade others when they have false or ill-considered views. John Stuart Mill position requires both not interfering with and actively strengthening autonomous expression, whereas Immanuel Kant’s entails a moral imperative of respectful treatment of persons as ends in themselves. In their different ways, these two philosophers both support the principle of respect for autonomy.

In contemporary applied ethics, autonomy is a very important concept. In some theories of biomedical ethics, respect for autonomy occupies center stage as either the only or the most important moral consideration. Health care professionals, especially in health care ethics, have developed a number of frameworks within modern applied ethics. Respect for autonomy is an important moral principle in a number of these frameworks. In the four-principle approach developed by Tom Beauchamp and James Childress, and popularized in Europe by Ranaan Gillon, respect for autonomy is one of four basic moral principles together with nonmaleficence, beneficence, and justice. In the last subheading of this chapter, I shall outline briefly these other related principles and some relevant concepts. Having traced the historical development of the concept of autonomy from the ancient Greek to Kant, Mill,
Beauchamp and Childress, let us now consider some types of autonomy in what follows.

1.3 TYPES OF AUTONOMY.

Raanan Gillon made a distinction of autonomy, namely, autonomy of action, autonomy of will, and autonomy of thought.\(^4\)

**Autonomy of thought** embraces the wide range of intellectual activities that are called “thinking for oneself”, including making decisions, believing things, having aesthetic preferences, and making moral assessments.

**Autonomy of will** (autonomy of intention) is the ability/capacity to decide to do things on the basis of one’s deliberations. For the ordinary man and his doctor, there is not much doubt that there is a human capacity corresponding to the idea of willpower (to the idea, for example, that one can decide to do, or not to do, something despite a powerful contrary desire and then act accordingly). However, there is little doubt that some people have more of such autonomy of will than others, that it is variable in all of us, and that it may be diminished by among other things, disease and chemical agents.

**Autonomy of action**- is the ability to perform an act. It is the freedom to act autonomously. The patient whose voluntary muscles are paralyzed by curariforms but who is conscious because his anesthetist has forgotten the nitrous oxide and who tries in vain to devise a way of stopping the surgeon cutting him is perhaps a paradigm of a person whose autonomy of thought and will are active, but whose autonomy of action is temporarily completely absent.

Beauchamp and Childress did not make this distinction. However, they maintained that almost every theory of autonomy agree that the two conditions of liberty and agency are necessary for autonomy.

1.3. OTHER RELEVANT CONCEPTS AND PRINCIPLES.

There are three other related principles and some other relevant concepts we cannot undermine in the treatment of the principle of respect for autonomy. The principle of respect for autonomy is but only one out of a set of principles, which according to Beauchamp and Childress should function as an analytical framework that expresses the general values underlying rules in the common morality. Other principles in the framework are the principle of nonmaleficence, the principle of beneficence, and the principle of justice.

**The principle of nonmaleficence** asserts an obligation not to inflict harm on others. In medical ethics, according to Beauchamp and Childress, it is associated with the maxim *primum non nocere*; “above all (or first) do no harm”. Many types of ethical theories, including both utilitarian and nonutilitarian theories, recognize a principle of nonmaleficence; while some philosophers combine nonmaleficence with beneficence in a single principle. This principle supports many more specific moral rules like, *do not kill, do not cause pain or suffering, do not incapacitate, do not cause offense, do not deprive others of the goods of life.*

**The principle of beneficence** may be described as the positive expression of nonmaleficence. This principle highlights that we have a positive obligation to advance the healthcare interests and welfare of others, to assist others in their choices to live life to the fullest. Beauchamp and Childress have described beneficence as a way of ensuring reciprocity in our relationships; i.e. we have a responsibility to help others because we have ourselves received benefits. The risk of harm to oneself represents a legitimate limit to our obligation to be beneficent.

**The principle of justice** in relation to healthcare, justice may be described as the allocation of healthcare resources according to a just standard. There are two basic types of justice. *Comparative justice* involves balancing the competing claims of people for the same health care resources. It is only necessary because of the fact that health funding is not unlimited – if there were plenty of everything, there would be no need to allocate or prioritize resources. In comparative justice what one receives is determined by one’s
particular condition and needs. *Distributive justice*, on the other hand, determines the distribution of health care resources by a standard that is independent of the claims of particular people. For this reason it may also be called ‘noncomparative’ justice. Distribution is determined according to principles rather than individual or group need. However, it may be right to say that comparative justice is a kind of distributive justice, giving the distinction above.

There is allegedly no lexical ordering of the four principles, and moral decisions about specific cases is carried out by (a) identifying the relevant principles, (b) specifying how they apply to the current situation, and (c) balancing between the consideration generated by steps “a” and “b”. Because of the centrality of paternalism in decision-making in health care ethics, it is essential to briefly talk about the concept of paternalism.

**Paternalism**

The definition of paternalism most widely cited is Gerald Dworking’s:

(Paternalism is) the interference with a person’s liberty of action justified by reasons referring exclusively to welfare, good, happiness, needs, interests, or values of the person being coerced.⁵

When paternalism in a legal system is at issue, this definition is acceptable since laws, backed by force or the threat of harm, are by nature coercive. However, many of the actions considered paternalistic in biomedical ethics do not fit this definition. In biomedical ethics, it is the ethical stance that a person’s autonomy is justifiably restricted to prevent self-harm. It is grounded in the principle of beneficence.

As a "liberty-limiting" approach, paternalism is usually grounded in a theory of impairment: namely, that an individual lacks sufficient facts or mental capacity to make a sound choice. It is sometimes defended by a theory

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of future consent: viz., that the person whose liberty is circumscribed will (or, at least in principle, could) eventually agree that the restriction was desirable, given better facts or improved cognitive capacity in future.

**Informed Consent**

Informed consent is the process by which a fully informed patient can participate in choices about his/her health care. It originates from the legal and ethical right the patient has to direct what happens to his/her body and from the ethical duty of the physician to involve the patient in his/her health care.

The most important goal of informed consent is that the patient has an opportunity to be an informed participant in his/her health care decisions. It is generally accepted that complete informed consent includes a discussion of the following elements:

- the nature of the decision/procedure
- reasonable alternatives to the proposed intervention
- the relevant risks, benefits, and uncertainties related to each alternative
- assessment of patient understanding
- the acceptance of the intervention by the patient

In order for the patient's consent to be valid, he must be considered competent to make the decision at hand and his consent must be voluntary. It is easy for coercive situations to arise in medicine. Patients often feel powerless and vulnerable. To encourage voluntariness, the physician can make clear to the patient that he is participating in a decision, not merely signing a form. With this understanding, the informed consent process should be seen as an invitation to him to participate in his health care decisions.
2.0. BEAUCHAMP AND CHILDRESS’S DEVELOPMENT OF THE FOUR PRINCIPLES.

I will start by clearing any bias on this subheading that may accuse me of any digression from the treatment of respect for autonomy to the treatment of the four principles. My reason for choosing this subheading is because it is in talking about Beauchamp and Childress’s development of the four principles that you can clearly understand their development of the principle of respect for autonomy. Having stated this, I will go ahead briefly to develop this subheading.

In the mid-to-late 1970, Beauchamp and Childress developed their set of principles, which I outlined in the first chapter of this work. They did this specifically for biomedical ethics and never presented it as a comprehensive ethical theory. Their theory is not the only principle-based approach in bioethics, because in the early history of modern bioethics, principles were invoked to provide frameworks of general guideline. Thus Beauchamp writes,

Principles gave an anchor to a youthful bioethics in the 1970s and early 1980s and contributed a sense that the field rests on something firmer than disciplinary bias or subjective judgment.¹

Although the principles in their framework are grouped under four general categories, the principle of respect for autonomy is the only one I will discuss at large. By so doing, I am not construing respect for autonomy as a principle with priority over all other moral principles. Beauchamp and Childress also made this point clear when they wrote,

We also maintain that construing respect for autonomy as a principle with

priority over all other moral principles, rather than one principle in a framework of prima facie principles, gives it too much weight.\textsuperscript{2}

I chose to write only on this version because health care professionals traditionally neglected this part of morality among others. Beauchamp and Childress’s structure of principles went beyond this tradition, by including the principle of respect for autonomy, among other parts of morality that traditionally have been neglected. Since that time, modern American biomedical ethical thought has been widely criticised for its preoccupation with patient autonomy. Beauchamp made an allusion to this when he said,

Health professionals’ obligation and virtues have for centuries been framed by professional commitments to provide medical care, to protect patients from the harms of disease, injury, and system failure, and to produce benefits that compensate for harms introduced. These obligations have been expressed through rules of nonmaleficence and beneficence, and our principles build on this tradition. But our structure of principles also reaches beyond these commitments by including parts of morality that traditionally have been neglected, especially respect for autonomy and justice.\textsuperscript{3}

Having stated this, I will go ahead in what follows to discuss the role of respect for autonomy.

\textbf{2.1. THE ROLE OF THE PRINCIPLE RESPECT FOR AUTONOMY.}

Respect for autonomy has become the centerpiece of medical ethics over the past thirty to forty years. People must be able to make decisions regarding their care, and have these wishes respected by the health care team. Respect for the autonomous choice of persons runs deep in common morality. There is divergent opinion concerning its nature, scope, or strength. A recurrent complaint about the four principles approach is that although in theory it claims

\begin{footnotesize}
\begin{itemize}
\item[\textsuperscript{2}] Tom L. Beauchamp and James F. Childress, \textit{Principles of Biomedical Ethics}, (5\textsuperscript{th} ed.), New York: Oxford University Press, 2001, p.104
\item[\textsuperscript{3}] Tom Beauchamp, “Principlism and its Alleged competitors”, in \textit{Bioethics}, ibid. , p.480.
\end{itemize}
\end{footnotesize}
not to prioritise any one of the principles. In practice respect for autonomy recurrently is prioritised. Thus Dan Callahan writes,

Autonomy is, then, de facto given a place of honour because the thrust of individualism, whether from the egalitarian left or the market oriented right, is to give people maximum liberty in devising their own lives and values.

However, in this work, the concept is used to examine individuals’ decision-making in health care, especially informed consent and refusal.

Virtually all theories of autonomy agree that two conditions are essential for autonomy, namely, liberty and agency. Still there exist ambiguity over the meaning of the two conditions and over whether more conditions are needed. Some writers maintain that autonomy is a matter of having the capacity to reflectively control and identify with one’s basic (first order) desire or preferences through higher-level (second order) desires or preferences. Beauchamp and Childress illustrated this with the example of an alcoholic who may have the desire to drink, but also a higher-order to stop drinking. An autonomous person in this account is one who is able to rationally accept, identify with, or repudiate a lower-order desire independently of others’ manipulation of that desire. Such acceptance or repudiation of first-order desires at the higher level (that is, the capacity to change one’s preference structure) constitutes autonomy. They observed that serious problems confront this theory, since acceptance or repudiation can be motivated by an overriding desire that is simply stronger, not more rational or autonomous. In their own analysis, the analysed autonomous action in terms of normal chooser who act

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5 Liberty in this context refers to independence from controlling influences.
6 Agency in this context refers to the capacity for intentional action.
(1) intentionally, (2) with understanding, and (3) without controlling influences that determine their action.\(^9\)

However, they maintain that the first of the three conditions is not a matter of degree, since “acts” are either intentional or nonintentional. It is important also that action have an intention, otherwise it may not qualify as action. But based on the second and third conditions, actions can be autonomous by degree, since acts can satisfy both conditions of understanding and absence of controlling influence to a greater or lesser extent. Thus they observed that for an action to be autonomous in this account, it needs only a substantial degree of understanding and freedom from constraint, not a fully understanding or a complete absence of influence. Their reason for arriving at this conclusion is because according to them, to restrict adequate decision-making by patients to the idea of fully or completely autonomous decision-making, strips their acts of any meaningful place in the practical world, where people’s actions are rarely, if ever, fully autonomous.\(^10\)

From the foregoing, it can be said that the role of the principle of respect for autonomy is better understood in the context of examining individuals’ decision-making in health care, especially informed consent and refusal. Thus informed consent also offers the clearest demonstration of the role of patient autonomy in medicine. The role of this principle has raised variety of questions in applied health care ethics:

What is autonomy? Why should we respect autonomous choices?

Should respect for autonomy mean that a person can request assistance in ending his/her life? Does respect for autonomy mean that a patient can request treatment that the clinician does not think is in his/her best interests, or treatment that is futile? Does it require us to consult them and obtain their consent before we do anything in the bid to help them? Who has the upper hand in decision-making? It is the physician or the patient? What is the

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\(^9\) Ibid., p.59.

\(^10\) For a detailed account of their argument, see the third chapter of Beauchamp and Childress’ *Principles of Biomedical Ethics*, (5th ed.).
intimate connection between autonomy and decision-making, especially when the conflicts and moral dilemmas in specific cases are so deep?

In what follows therefore, I will go ahead to discuss the intimate relation between autonomy and decision-making in health care ethics.

2.2. THE INTIMATE CONNECTION BETWEEN AUTONOMY AND DECISION-MAKING IN HEALTH CARE ETHICS.

The intimate connection between autonomy and decision-making in applied health care, especially in various kinds of consent and refusal has taken center stage in medical ethics since the Salgo decision in 1957. **Prior to that time, the physician’s supposedly moral duty to provide appropriate medical care typically surpassed the legal obligation to respect patient autonomy. The Salgo decision concluded that physicians have a legal duty to provide facts necessary for the patient to make an informed decision. "The doctor knows best" long ago was replaced with "The doctor proposes; the patient disposes." There is no legal obligation for the patient’s choice to be palatable to anyone, other than that patient herself. Although Beauchamp and Childress justified the obligation to solicit decisions from patients and potential research subjects by the principle of respect for autonomy, they however, acknowledged that the principle’s precise demands remain unsettled and open to interpretations and specification. While it is true that some writers in bioethics seem to affirm a duty of medical decision-making by patients, Beauchamp and Childress do not. Thus they wrote,**

While it is true that some writers in bioethics seem to affirm a duty of medical decision-making by patients, we do not. We defend a

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11 The 1957 case “Salgo versus Leland Stanford Jr. University Board of Trustees”, involved a 55-year-old male with leg cramping and other symptoms of extensive arterial disease. The patient underwent translumbar aortograph by a surgeon. There was no apparent complication to the procedure, although the next morning the patient awoke paralyzed from the waste down. The patient claimed that his physicians had not warned him of the risk of paralysis.

12 Some of the writings of Robert Veatch and Haavi Morreim, for example, seem to suggest such an ideal or duty. See also Schneider’s analysis in his *Practice of Autonomy*. 
principle of respect for autonomy with a correlative right to choose
(not a mandatory duty to choose).\textsuperscript{13}

In another variation, the role of autonomy in decision-making in the
Emergency Department (ED) has been inadequately explored. Asa W. Viccellio defended this view.\textsuperscript{14} In contrast to a less pressured outpatient setting, patients in the Emergency Department are asked to make judgments about treatment and disposition that may have immediate life-and-death consequences, and in highly charged emotional circumstances. This increases the likelihood of a decision, which a patient would not consider to be in her best interests in calmer circumstances. There are clearly established circumstances where a physician may, in fact, overrule the desires of a patient. Examples include patients who are suicidal or homicidal, and patients with a clearly impaired mental status related to medical illness. Less clear, but equally important, are patients whose mental status may be appropriate, but who are grossly unstable (e.g. a life-threatening low blood pressure associated with internal bleeding). Occasionally, we will see a patient who appears appropriately oriented, but simply will not acknowledge in any way the information being shared with her. For instance, after explaining that a patient’s chest pain is indicative of a heart attack, the patient responds, "I’m fine, my pressure’s a little high." The patient simply refuses to discuss the information provided. In such a circumstance, the patient will not, or cannot, demonstrate an understanding of the information, in which case the physician cannot ascertain whether the patient actually understands the possible nature of the problem. Although this is a gray area, many physicians will provide necessary care over the patient’s protests, unless the patient subsequently demonstrates an understanding of the advice being refused. According to Asa, the case below represents a more subtle variation of this.

Consider the transformation from "person" to "patient," undergone by an individual experiencing new symptoms.

\textsuperscript{13} Tom L. Beauchamp and James F. Childress, \textit{ibid}, p.61.
The person must first acknowledge her symptoms, consider their possible causes, and decide that the symptoms are beyond her capacity to deal with them alone, and finally to seek care. Becoming a "patient" implies that control over the decision and outcome of symptoms experienced are, to some degree, shared with someone else. This may first be a friend or loved one, who may (rightly or wrongly) reassure or express alarm. If the patient is not reassured, she may now seek medical care, i.e. complete the psychological transformation to becoming a "patient." Some older studies suggest that this last step occurs approximately 10% of the time, regardless of the actual medical seriousness of the symptoms. Thus, 90% of the time, concerns about newly experienced symptoms are dealt with in the immediate environment, without resort to medical evaluation.

This transformation, or lack of it, may play a critical psychological role in decision making in the Emergency Department. A person who, minutes before, was feeling quite well and completely immersed in her day-to-day activities, suddenly finds herself in the Emergency Department, often without her specific consent, perhaps cajoled by friend, family, or coworker who called for an ambulance. In one Emergency Medical Services (EMS) study, the person brought by the ambulance made the phone call four times out of one thousand. In other words, someone else’s call summoned the ambulance 996 times out of one thousand. Such a person arriving in the Emergency Department, still in the "person" mode, may be quite resistant to any efforts of the Emergency Department staff, and may refuse to embrace even the notion that she is experiencing an emergency. The driving force in her decision-making in this circumstance is more predicated on reflexively maintaining control, rather than on a serious reflection on the medical issues at hand. This need to maintain control, entirely appropriate in any of us, can undermine the patient's immediate needs, and the patient's long-term interests.

Let us consider the following case, not atypical for the emergency department:
A 45 year-old stockbroker experiences chest pain while at work. Initially reassured by a co-worker that it was probably indigestion, she continues her work. The pain returns, associated with sweating and nausea. Her colleagues, concerned by her appearance as well as her symptoms, insist that an ambulance be called, over her objections. She arrives at the Emergency Department, having refused monitoring, oxygen, or an intravenous in transit. She tells the physician that she feels fine, and that she had experienced a minor twinge of pain, which she felt sure, was nothing of consequence. She denies all other symptoms, and is insistent upon being released. After negotiation with the physician, she reluctantly agrees to an Electrocardiography (EKG)15 "just to prove us wrong," but no other tests. An Electrocardiography (EKG) shows an acute inferior wall myocardial infarction. When presented with this information, the patient continues to insist upon leaving, stating that she will be fine. The physician discusses the diagnosis and consequences at length. The patient continues to refuse care. She offers to sign any forms necessary to release the doctor and hospital of any responsibility. There are no family members or co-workers present to assist in convincing her to stay. The treating physician discusses in great detail the consequences of the diagnosis, and what is necessary for treatment. It is explained that there is a high likelihood of death should the patient leave. The physician offers to call in another physician for a second opinion, or to transfer her to a facility of her liking. The patient is completely oriented, her vital signs are, for the time being, stable, and she is not suicidal. She seems to demonstrate an understanding of her diagnosis, as

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15 Every time the heart beats, tiny electrical impulses are discharged. Using a process called electrocardiography, those electrical discharges can be recorded and used to measure the heart's condition. Several thin wires are attached to the body. The wires conduct the electrical charges into a machine that measures them and produces readout. Since most electrocardiograms show a healthy heart for patients at rest, doctors take the readout while the patient is under the stress of strenuous activity. Stress electrocardiography reveals a different picture of the heart's health. Usually, the patient walks on a treadmill machine while the heart readings are taken.
well as the consequences.\textsuperscript{16} Must the physician now respect the patient’s right to make her own decision?

One cannot ignore the volatile nature of decision making in the Emergency Department setting. Consider, in contrast, a decision regarding chemotherapy in a cancer patient. The choices may be quite complex. Yet in most circumstances, the patient has time to reflect on the consequences of her choices, to discuss them at length with the physician, with her family and friends, and, importantly, to reflect on these choices in various moods and settings prior to arriving at a decision. Further information can be sought, questions generated and answered, and different perspectives incorporated into a final decision. Because of the time for reflection, there is a sense that the patient’s decision has a reproducible quality to it. There is also opportunity for a "final" decision to be revisited, and changed. The patient above, with the myocardial infarction, however, does not appear to fully embrace the information given to her, in spite of her ability to demonstrate an understanding of what is being said. Her decision is, in the judgment of the physician, superficial, reactionary, and impulsive. She is not yet psychologically ready to participate in the pursuit of her diagnosis and treatment. Although she may mouth an understanding of what has occurred, she appears detached from the reality of what is happening. In spite of "informed dissent," the physician nonetheless believes that the patient is in an active state of denial regarding the serious nature of her problem. Usually, health care providers try to buy time to allow patients to reflect on their decision (and complete the transition from "person" to "patient"), and to involve family and friends in an effort to persuade patients to stay in the hospital. In this particular case, however, the patient is not allowing the physician to "buy time," and no family or friends are available. There is a reasonable likelihood that, if this patient leaves, there will be no opportunity to revisit her decision, because she may die. Her treating physician ignores her wishes, and admits her "against her will." If necessary, the physician will use chemical restraints (sedation) to keep her here.

\textsuperscript{16} Asa W. Viccellio, ibid.
As noted above, physicians have a well-established authority to act to protect patients who are suicidal, psychotic, or mentally incapable of making a medical decision. One can to some degree extend this to patients who do not respond to information provided in such a fashion as to demonstrate an understanding of the medical care they are refusing. This case, however, rests solely on the belief of the physician that the patient cannot respond appropriately out of fear or denial, even though she echoes an understanding of the problem. How could one so readily ignore the patient’s right to autonomy? One may argue that patients must have the right information and be in an appropriate frame of mind in order to meaningfully exercise their capacity to make their own decisions. Many people present to the emergency department in severe pain, scared, and angry. Suddenly thrust into a set of circumstances beyond any previous life experience, they are asked to make reasoned decisions, within minutes, under physical and emotional duress, which may have lifelong (or life-ending) consequences. The capacity for denial may exceed the physician's best efforts to inform. It is critical for the physician to determine whether they are hearing the patient’s judgment, or the patient’s anger, fear, and pain. So, in the case described above, one can say that it is not the patient’s autonomy, which is being ignored, but the frivolous perversion of it. It is necessary for the physician to know that she is hearing the true "heart and mind" of the patient.

Patients commonly refuse treatment when the information is first presented to them, but subsequently arrive at a different conclusion. What changes is not the information, but the patient’s psychological state, i.e. their successful negotiation of the path from "person" to "patient," which now allows them to fully acknowledge that circumstances exist which are beyond their ability to cope alone. It is a transition that, interestingly, can be remarkably abrupt. It is also a transition that occurs with greater difficulty in a patient with no prior similar experience with medical illness. If the patient above had experienced a previous myocardial event, her assent to care would most likely occur quite
readily. If she refused care, her reasoning would probably also be much clearer to the physician.

Sometimes, patients who come willingly to the Emergency Department reverse their decisions. Circumstances related to the patient’s care may precipitate a crisis of confidence, and the patient now wishes to leave. Negative personal interactions with the health care providers, prolonged waits, lab delays, and lack of inpatient beds are common reasons for patients leaving the Emergency Department, decisions driven by anger and frustration. In such instances, it is our own system that places the patient in jeopardy. Also, the patient may fundamentally lack trust in either the treating physician or the reputation of the hospital, and is making quite an appropriate decision to refuse care. In reality, in this circumstance where the physician acts against the wishes of the patient, there remains no guarantee that the physician’s diagnosis is correct, in spite of evidence, which is "obvious" to the physician.

In the case related above, the physician is virtually certain of the diagnosis, and of the consequences. How adamant would the same physician be if there were a 50%, or 5% likelihood of an acute myocardial infarction, or if the physician felt that the patient was truly absorbing and responding to the information being presented? There may be very important, non-medical issues in the patient’s life, which make it extraordinarily difficult for the patient to stay in the hospital. For example, one has to pick up her child at school; another cares for an incapacitated parent at home; a pet will be abandoned. In the absence of a willing family member or friend, there is frequently little we can offer to resolve these issues. The lack of faith in a particular institution or particular physician cannot be ignored as critical to a patient's decision making. In short, the physician must negotiate in the face of diagnostic uncertainty, and in the face of truly legitimate issues either central or quite peripheral to the care needed.

The foregoing discussion on the intimate relation between autonomy and decision-making in health care ethics will be incomplete without a word on
surrogate decision-making. In what follows therefore I shall discuss briefly surrogate decision-making.

2.2.1. **SURROGATE DECISION-MAKING.**

Surrogate decision-making can be simply defined as a durable power of attorney for health care (or a health care proxy appointment), which designates another person to make health care decisions on behalf of the patient. Various forms of the loss or absence of competency can raise the issue of surrogate decision-making. Medically difficulty cases may require a fair bit of consultation, and the burden of decision should not be placed solely on health care professionals. This might seem a largely legal issue, but choosing surrogate decision-makers and knowing when they should be removed from their positions are also ethical decisions. Family members are obvious first choices, but they may have conflicts of interest or other impediments to functioning well as surrogates. Supposedly neutral third parties may have unforeseen ethical objections to certain procedures or decisions that make them unfit.

Decision-making for incompetent patients is a troubling ethical problem. In fact, to my mind, it has been the troubling ethical problem for the last fifteen or twenty years, at least since the Karen Quinlan case of 1976. Because these patients cannot speak for themselves, courts and legislatures, at least since 1976, have developed an approach to end of life decisions that allows parties-surrrogates-to make decisions for the incompetent person.

The underlying assumption that permits surrogate decision-making in most countries is that incompetent patients have a right to self-determination similar to that of competent patients. The basic rule here is that one employs a substitute judgment standard. By substitute judgment, the courts have meant that one tries to substitute one's own judgment for what the judgment of the now incompetent would be if the incompetent were able to speak for himself or herself. There are ways we can discover the incompetent person's judgment. People can write us things in advance such as Living Wills or other directives.
People can talk to us or to their doctors and say what they want, or they can live a life with a set of values and beliefs that can be perceived by a third party. There is an alternative standard that most courts have shied away from whenever a substitute judgment could be made: the best interest standard. The substitute judgment standard is a subjective standard. It doesn't say, what would most people want in these circumstances? Rather, it says, what would the incompetent person want in these circumstances based on who the incompetent person is and what her values structure is.

Up until now, courts have shied away from the best interest standard except in instances where the individual's subjective values are unknown. Those instances might be John Doe cases brought to an emergency room without known relatives, and irreversibly incompetent. Or they might be persons born with profound mental retardation and never able to express their wishes. In cases like these the courts might resort to an objective standard. In objective standard, one presumably doesn't know or perhaps knows but doesn't care, what the subjective values of the individual are and imposes some external notion of the person's best interests.

2.3. THE SCOPE OF ITS APPLICATION.

This section will briefly examine the application of the principle of patient autonomy within bioethics. In complex societies such as those found in North America and Europe patients from diverse ethnic, cultural, and religious backgrounds increasingly confront health care professionals. This affects the relationship between clinicians and patients to the extent that patients' deliberations upon the proposed courses of treatment can, in various ways and to varying extents, be influenced by their ethnic, cultural, and religious commitments.

We may agree on our substantive moral commitments, we may agree on our moral obligations in terms of respect for autonomy, and yet we may still disagree, perhaps radically, about its scope of application. Thus Raanan Gillon asks,
…even if we agree that the scope of the principle of respect for autonomy is universal, encompassing all autonomous agents, just who or what counts as autonomous (or adequately autonomous) agent?16

Gillon observes that two issues of scope that are of particular practical importance to health care workers. The first is the question: who falls in the scope of the prima facie principle of respect for autonomy? The second is: what is the scope of the widely acknowledged ‘right to life’- who, and indeed what, has a ‘right to life’? Obviously only autonomous agents can fall within the scope of the principle of respect for autonomy- one simply cannot respect the autonomy of a winter shoe or jacket, nor of anything else that is not autonomous. But who or what counts as an autonomous agent?

When we disagree about whether or not to respect the decision of a girl of fourteen to take the oral contraceptive pill, we are in effect disagreeing about the scope of application of the principle of respect for autonomy. Similar questions about the scope of respect for autonomy arise in other paediatric contexts, in care of the severely mentally impaired, and in care of the elderly when those elderly are severely mentally impaired, as by dementia.18 Some patient clearly do not fall within the scope of respect for autonomy- newborn babies, for example, are not autonomous agents, for autonomy requires the capacity to deliberate.

17 Paediatrics is concerned with the health of infants, children and adolescents, their growth and development, and their opportunity to achieve full potential as adults.
18 Dementia is an organic mental disorder characterized by a general loss of intellectual abilities involving impairment of memory, judgment and abstract thinking as well as changes in personality. It does not include loss of intellectual functioning caused by clouding of consciousness, nor that caused by depression or other functional mental disorder (pseudo dementia). Dementia may be caused by a large number of conditions, some reversible and some progressive, that cause widespread cerebral and damage or dysfunction. The most common cause is Alzheimer's disease, others are cerebrovascular disease (multi infarct dementia), central nervous system infection, brain trauma or tumors, pernicious anemia, folic acid deficiency, normal pressure hydrocephalus, and, neurological diseases such as Huntington disease, multiple sclerosis and Parkinson's disease.
The question that comes to mind at this point is, how much capacity for logical thought and deliberation, and what other attributes are required for somebody to be an ‘adequately autonomous agent’? These philosophical questions are answered; in the context of health care and the “World Medical Association Declaration of Helsinki”\(^\text{19}\) it is acknowledged that the autonomy of even quite young children and of quite severely mentally impaired patients are prima facie to be respected unless there are good moral reasons not to do so. Moreover, those reasons will be highly context-relative- a young child, or a severely mentally impaired patient, may not be adequately autonomous to have decisions to reject an operation respected, but be entirely adequately autonomous to decide what food to eat or what clothes to wear. Where patients are not adequately autonomous for their decisions to be respected, and if those decisions appear to be against their interests, important issues arise concerning who should be regarded as ‘proper proxies’ to make decisions on their behalf, and on what criteria. I discussed this earlier in the treatment of the intimate connection between autonomy and decision-making in applied health care.

2.4. APPLICATION IN RELATION TO OTHER PRINCIPLES.

Concerning the application of the four principles in relation to each other, a persistent criticism has been directed to principlism for its inability to articulate strategies for deciding between principles when they are in conflict in any particular case. Paul Root Wolpe buttresses this point thus,

Because Beauchamp and Childress intentionally refused to offer a priority weighing or hierarchical ranking of their four principles, a persistent criticism of principlism has been its inability to articulate strategies for deciding between principles when they are in conflict in any particular case or when weighed differently by different parties in a case.\(^\text{20}\)

\(^{19}\) World Medical Association Declaration of Helsinki, art. 25, June 1964.
In brief, the application of the principle of respect for autonomy and the other three principles depend on the principle that weighs more in a particular case, culture and religion. They can be harmonized differently in the same particular case, depending on the particular culture’s norms of harmony. Thus one culture may give greater ‘dominance’ to beneficence at the expense of say autonomy (for instance the Nordic culture), another may prefer the cool harmonies provided by the predominance of justice, and yet another culture may prefer the perhaps more dissonant harmonies resulting from frequent predominance of respect for autonomy. Beauchamp and Childress are of the view that in stubborn cases of conflict, there may be no single right action, because two or more morally acceptable actions are unavoidably in conflict and yet have equal weight in the circumstances.

Beauchamp and Childress deny that their theory makes it impossible in general to distinguish between competing applications of principles. In conflicting circumstances of principles there may be need for further specification, gradually eliminating the dilemmas and circumstances of conflict. There are however, tangled problems about the best method to use in order to achieve specification. The model of analysis for reaching specification and justification in health care ethics that Beauchamp and Childress long used is that of a dialectical balancing of principles against other encountered moral considerations, in an attempt to achieve general coherence.
3.0. SCOPE OF APPLICATION IN CASES.

Beauchamp and Raanan Gillon share the view that it is legitimate and rewarding to diagnose cases through the lens of general ethical principles. In this chapter, I will outline some cases in health care ethics that has generated a debate concerning the application of the principle of respect for autonomy, precisely, ‘the standard Jehovah witness case’, ‘the child of a Jehovah witness case’, and ‘Helga Wanglie case’.

3.1. THE ‘STANDARD’ JEHOVAH’S WITNESS CASE.

In the first scenario, that of the "standard" Jehovah’s Witness case, a competent adult patient loses a massive amount of blood from a blood vessel bleeding in an acute duodenal ulcer. The best chance of saving his life is an urgent blood transfusion along with operative intervention to arrest the bleeding. The patient refuses blood but asks for treatment instead with the best available non-blood products, and surgery, accepting the substantial risk that surgery without blood transfusion is much less likely to save his life than surgery with blood transfusion.

Raanan Gillon analyses this case along standard four principles lines, and concludes: that the patient’s wishes ought to be respected because, briefly summarised, the patient’s autonomy is thus respected, the patient’s own assessment of harms and benefits for himself in addition leads the patient to conclude that far more harm over benefit would result for him from a life saving blood transfusion than from death without a blood transfusion, without countervailing overall harm and benefit assessments overruling this personal assessment; that rights based justice and legal justice allow him to refuse even life prolonging treatment, and that though non-blood alternative treatments may be more expensive than blood transfusions, they are not so disproportionally
more expensive that it would be wrong to use them if available—and if they were disproportionately expensive he would be prepared to forgo them.¹

According to Beauchamp in his own analysis, standard treatment of the "standard" case in this first scenario is to specify the commitments of the principle of respect for autonomy for those contexts in which the religious commitments of a patient conflict with the healing commitments of health care professionals or institutions.² To look for an appropriate specification in the case before us, he considers two moral rules that have come into conflict in this first scenario:

1. It is morally prohibited to risk death for a patient whose life threatening condition can be medically managed by suitable medical techniques.
2. It is morally prohibited to disrespect a first party refusal of treatment.

He continued by saying that in a wide variety of cases—well beyond those involving religious commitments—patients refuse promising treatments offered by medical officials. Sometimes these patients are concerned about the consequences of treatment, but often their decisions rest on principled convictions or specific objectives that exhibit little or no concern with medical consequences. For example, these patients may not find the treatment worth the cost, may not trust their doctors, may wish to die, or may have religious objections to an intervention.

To handle conflicts between the obligation to treat and the obligation to respect a refusal, it is now widely accepted that rule 2 should be specified as follows in order to handle the problem of a contingent conflict with rule 1:

2.1. It is morally prohibited to disrespect a first party refusal of treatment by a patient, unless the refusal is non-autonomous and presents a significant danger to the patient.

Rule 2.1 qualifies as a specification because much of the content of the original rule (2) remains intact.

Rule 2.1 states that a physician is not absolutely required to respect refusals of treatment, but that the range of exceptions is narrow. This rule has the simple but powerful effect of informing medical officials (indeed, everyone) that all truly autonomous refusals of treatment must be respected, no matter the consequences.

There is no evidence in the scenario before us to indicate that the patient has made other than an autonomous choice, though nothing in this case indicates whether the choice by the patient was *adequately* autonomous. Some moral philosophers have argued that autonomous action is incompatible with the authority of religious organisations and political communities that legislate persons’ principles and decisions. They maintain that autonomous persons must act on their own reasons and can never submit to the dictates of religious or political authorities.3 No fundamental inconsistency exists, however, between autonomy and authority if individuals exercise their autonomy in accepting the norms of the authority. Having autonomously chosen the authority of his religious institution, a Jehovah’s Witness has a reasonable basis on which to refuse a recommended blood transfusion. However, rule 2.1 may not be quite as unbending as Beauchamp’s analysis thus far suggests. Occasionally in medical ethics, an autonomy interest is minimal and a medical benefit maximal, warranting a *paternalistic* intervention by the physician. Justified paternalism of this sort constitutes another type of exception to rule 2. This exception is limited, however, to cases in which a vital or substantial autonomy interest is not at stake. This is not the case in the present scenario. The decision by this Jehovah’s Witness rests on a paradigmatically vital autonomy interest. To intervene coercively by compelling a transfusion could not be justified under any plausible condition of justified paternalism known to me.

3.2. THE CHILD OF A JEHOVAH’S WITNESS CASE.

A 2-year-old infant has lost a massive amount of blood in a road accident and again the best chance of saving the child’s life is an urgent blood transfusion and operative intervention to arrest the bleeding. Both the child’s parents are Jehovah’s Witnesses and refuse to give permission for a blood transfusion, requesting instead that the best available non-blood products are used to restore volume and that surgery is carried out without blood. They understand that this will be a far more dangerous course of action than surgery plus blood transfusion but persist in refusing permission for a blood transfusion for their child. The surgeon in charge tells them there is no time to argue about the issue, and he is cross matching blood for transfusion and will administer the blood against the parent’s instructions in order to save the child’s life. He has instructed the hospital’s lawyer to try to obtain urgent court approval of his action, and they are welcome to argue their case with the court but he intends to transfuse the child unless a rapid decision by a judge forbidding him to do so is produced in time to prevent him.

According to Beauchamp, the following two rules conflict in this second scenario:

1. It is morally prohibited to risk death for a patient if his or her life threatening condition can be medically managed by suitable medical techniques.
2. It is morally prohibited to disrespect a parental refusal of treatment.

He goes further to argue that, in many circumstances, beyond but including those involving religious commitments, parents refuse treatment for infants in the conviction that the infant’s overall best interest is served. To handle such conflicts, rule 2 can be specified as 2.1:

2.1. It is morally prohibited to disrespect a parental refusal of treatment, unless the refusal constitutes child abuse, child neglect, or violates a right of the child.

Rule 2.1 qualifies as a specification because much of the content of the original rule remains intact, but now we understand that a medical professional is only generally required to respect parental refusals of treatment. Rule 2.1 is a start,
but only a start, down the path of specification. It will not handle all cases and will need further examination of child abuse, child endangerment, child neglect, and the rights of children. None the less, 2.1 does show that there is a path out of the initial conflict between rules 1 and 2, and it indicates that physicians and hospital administrators are not confronted with an absolute rule requiring that medical officials uphold parental refusals. With enough additional specification, an entire hospital policy could be constructed that is generally adequate to process the range of cases of parental refusal that surgeons, paediatricians, and those in other specialties might expect to see.

Assuming that 2.1 is an acceptable specification, what action should be performed in the second scenario? His view is that it is morally required—not merely morally permitted—to overrule this parental refusal of treatment, because the refusal does constitute a form of child abuse, child endangerment, child neglect, or inattention to the rights of the child. Many forms of neglect, abuse, and endangerment of children have occurred in the name of religion, and withholding a recommended medical therapy on the basis of religious convictions, causing a child’s preventable death, is one of them. Jehovah’s Witness parents who refuse lifesaving blood transfusions for their minor children have been widely considered in bioethics as a paradigm of overreaching parental authority.⁴ I accept this conclusion myself, but it must also be acknowledged that this judgment is not free of controversy.

Legislative bodies around the world have, over the course of the last century, wavered and reversed themselves over these issues. They have, on the one hand, passed statutes that allow for so called "religious exemptions" that permit parental religious convictions to prevail over recommended medical treatment. But when parents then make judgments that endanger children, many of these legislatures temper or rescind the very religious exemptions they previously allowed.⁵

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⁴ Tom Beauchamp, ibid.
In 1944 the United States Supreme Court decided, in the case of *Prince v Massachusetts*, that a Jehovah’s Witness parent could not neglect the education of her nine year old child by dictating that the child sell religious magazines on the street. In this case, Ms Prince argued that her religious beliefs were constitutionally protected, but the Supreme Court found that rights of religion are not beyond limitation and that a child cannot reasonably be subjected to a poor education, to communicable disease, to ill health, or to death. The court determined that parents may martyr themselves, but may not martyr their children.

Prince established in US law an important principle that should be no less pronounced in morals, namely that religious standards and practices must yield to sober medical judgment when they seriously affect the welfare and health of children. Nothing in the protection of religious belief, in law, or in morals, should allow for the neglect of a child’s appropriate medical treatment. More specifically, if a child faces a risk of death, disfigurement, serious bodily injury, or ill health a decision to withhold medical care constitutes parental abuse or neglect even if the parent’s reason is religious and reflective of the parents’ considered viewpoint.

Raanan Gillon analyses this case using what he has described as the "four principles plus scope" approach, concluding that the surgeon, if he cannot obtain parental consent to save the child’s life is morally right (and probably legally right) to override their refusal and administer a blood transfusion on the grounds (briefly summarised) that the child does not fall within the scope of the principle of respect for autonomy, and that the parents’ authority to decide on medical treatment for their child morally should not and legally does not extend to imposing severe and probably fatal harm on their child in the pursuit of their own religious beliefs rather than in what their society, though not their religion, regards as the child’s best interests.

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Although Gillon’s conclusion is correct, what is open to question is his claim that what society regards as the child’s best interest determines what really is in the child’s best interest. What criteria should be used to determine what is in a child’s best interest? Gillon’s answer is as follows: respect for decision of the parents “is conditional upon social agreement that those decisions are in their child’s best interests”. There is reason with Macklin’s observation that to adopt the criterion of “social agreement” would plunge us into the morass of cultural and ethical relativism. Should it be the consensus of the Jehovah’s Witness community in which the family lives that constitutes the relevant social agreement? Or must it be the social agreement of the majority of the country, say Sweden or UK or US, where the majority do not subscribe to the religious and metaphysical beliefs of Jehovah’s Witness? This is a matter that needs to be addressed.

3.3. **HELGA WANGLIE’S CASE.**

On 14 December 1989, Helga Wanglie, eight-six, broke her hip when she slipped on a rug in her Minneapolis home. After the hip fracture was successfully treated at the Hennepin County Medical Center (HCMC) she was discharged to a nursing home. She was re admitted to Hennepin County Medical Center on 1 January 1990 when she developed respiratory failure and was placed on a respirator. Over the next five months repeated attempts to wean Mrs. Wanglie from the respirator were unsuccessful. During this initial admission, Mrs. Wanglie was conscious, aware of her surroundings, could acknowledge pain and suffering, and could recognize her family. The hospital was unable to wean Mrs. Wanglie from the respirator, and on 7 May 1990 she was transferred to another facility that specializes in the care of respirator-dependent patients. When further attempts were made to wean her from the respirator at the new facility, she experienced a cardiopulmonary arrest on 23 May. She was resuscitated and then transferred to another acute

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7 Raanan Gillon, ‘Four Scenarios’, ibid, p.33.
care hospital in St. Paul. She was now felt to have extremely severe and irreversible brain damage. Because of this dismal prognosis, a hospital ethics committee reviewed her case and doctors discussed with the family the possibility of limiting further life-sustaining treatment. However, the family resisted this idea and requested that Mrs. Wanglie be transferred back to Hennepin County Medical Center, where they felt she had received excellent care.

Since readmission to Hennepin County Medical Center on 31 May 1990 the patient has been vigorously treated with continued respirator support, antibiotics for recurrent pneumonia, artificial feeding, and treatment for electrolyte and fluid imbalance. Initial diagnosis on readmission to Hennepin County Medical Center was persistent vegetative state secondary to severe hypoxic-ischemic encephalopathy. Over the next several months repeated evaluations by the neurology and pulmonary medicine services confirmed the diagnosis of permanent unconsciousness (persistent vegetative state), and permanent respirator dependency because of chronic lung disease.

Because of her age, previously prolonged hospital stays at Hennepin County Medical Center in early 1990, multiple medical complications, ultimately unsuccessful weaning from the respirator, and neurologic condition, the medical staff caring for Mrs. Wanglie viewed her prognosis as extraordinarily poor. They did not believe that the respirator could benefit her. However, the immediate family--her husband, daughter, and son--insisted that all forms of treatment be continued. In view of the fact that recovery from cardiac arrest would be extraordinarily unlikely, the family did reluctantly agree to a DNR order.

Oliver Wanglie understands that his wife is unaware of herself, her surroundings, and his visits. When asked if he understood the medical diagnosis and that the patient would not recover consciousness or improve in any significant way, he replied, "That may be true, but we hope for the best." The family's reluctance to discontinue treatment is based on religious and personal grounds. Mr. Wanglie has said that only God can take life and that
doctors should not play God. Prior to December he told hospital staff that his wife had not discussed these issues, and that her views were a "black box."

Because of the conflict between the medical staff's view of Mrs. Wanglie's dismal prognosis and the family's insistence on intensive treatment, the Hennepin County Medical Center ethics committee became involved in the case shortly after the second admission. The initial advisory opinion from the ethics committee was that hospital staff should err initially on the side of continuing treatment and following the wishes of the family, and make every reasonable attempt to resolve conflicts between the family's wishes and the views of the hospital staff. In late 1990 it became apparent that the conflict between the family's insistence on continued medical treatment and the hospital staff's strong feeling that further treatment was not indicated could not be resolved.

Several family conferences were held in November and December. The family was told that the attending physicians caring for Mrs. Wanglie had concluded that continued use of the respirator could not serve the patient's interests. On 3 December a conference was held with hospital staff, the Wanglie family, and Dr. Steven Miles, representative of the hospital ethics committee and petitioner in this case. After this conference, in a letter dated 3 December, Oliver Wanglie wrote,

My wife always stated to me that if anything happened to her so that she could not take care of herself, she did not want anything done to shorten or prematurely take her life.\(^9\)

In a letter to Mr. Wanglie the hospital's medical director responded:

All medical consultants agree with [the attending physician's] conclusion that continued use of mechanical ventilation and other forms of life-sustaining treatment are no longer serving the

patient's personal medical interest. We do not believe that the hospital is obliged to provide inappropriate medical treatment that cannot advance a patient's personal interest. We would continue life-sustaining treatment on the order of a court mandating such treatment. In view of the extraordinary nature of your request [to continue treatment], we ask that you file petition to obtain such an order by December 14.10

When it was obvious that the family refused to file a petition on its own, the hospital filed papers with the Fourth Judicial District Court, Hennepin County, on 8 February 1991. Medicare and Physicians’ Health Plan, a private supplementary insurance plan, reimburse the costs of Mrs. Wanglie’s care.

By the time this case was first heard in court on 28 May the costs for both hospitalizations (at Hennepin County Medical Center) were approximately $800,000.

The principal parties do not dispute most of the medical facts. The family accepts the diagnosis of persistent vegetative state and respirator dependence. The hospital is willing to let Mrs. Wanglie's family transfer her to another facility where she would continue to receive vigorous treatment, including respirator support. Both the hospital and the Wanglie family have made determined efforts to find another physician or health care facility in Minnesota willing to take Mrs. Wanglie in transfer. These efforts have; thus far, been unsuccessful, though other providers would be willing to care for her were she not respirator dependent.

The hospital is seeking appointment of a conservator (independent guardian) to represent the patient to decide whether continued treatment is appropriate. It is not directly requesting the court to discontinue treatment immediately over the objections of the family. In seeking court involvement, the hospital and its ethics committee are aware that there has never before been a case in the United States of a hospital seeking a conservator (independent guardian) to

10 Ibid.
consider non-treatment when the immediate family has strongly and unanimously objected. The major point of the hospital's current position is that the family cannot demand that physicians continue to give treatment that is not in the patient's best personal medical interest.

Mr. Wanglie simultaneously sought appointment as his wife’s guardian. The Probate Court denied the medical center’s petition, and appointed Mr. Wanglie to serve as Mrs. Wanglie’s guardian and to make treatment decisions on her behalf. The court stated that Mr. Wanglie was "the most suitable and best qualified person" to serve from among the available potential guardians for his wife. Three days after the order was issued, Mrs. Wanglie died “of natural Causes”.

Many have labeled this case a "futile treatment case," presumably because the medical centre sought to have appointed a guardian whom it believed would give consent to stopping treatment that the medical centre judged to be futile. However, the court decided the case strictly as a guardianship matter and did not address the appropriateness of treatment. According to Robert L. Schwartz, those who have viewed this case as dealing with futility in a scientific sense have brought the wrong perspective to the case. Robert thinks that the question is not whether the treatment offered would successfully do what Mrs. Wanglie’s family said she desired- keep her alive, but whether keeping her alive, under the circumstances was beyond the proper scope of medicine.\(^\text{11}\)

I agree with Robert’s argument. I therefore maintain that the real question in this case was whether the continuation of life-sustaining treatment for an 87-year old woman in a persistent vegetative state with no hope of returning to sentience constitutes treatment out side of the limits of medicine. Was the continuation of ventilator support and gastrostomy feeding among the reasonable medical alternatives that should have been available to her or her surrogate (whoever that might be)? Was the provision of this kind of treatment

in this kind of case outside the limits of medicine, thus beyond her power of choice? Must all available life – sustaining means always be used, or are there certain – ordinary or disproportionate means that need not be employed? This question throws light to the issue of ordinary/proportionate and extraordinary/disproportionate means. A mean is “proportionate” if and only if it offers a reasonable hope of benefit to the patient. It is “disproportionate” when the means of treatment does not offer a reasonable hope of benefit to the patient. I argue that Mrs. Wanglie’s case involves a disproportionate means and could be termed as prolongation of death since death might have occurred naturally without the life-sustaining treatment.

In another variation, since some patient like Helen Wanglie, clearly do not fall within the scope of respect for autonomy, owing to Dementia, which is an organic mental disorder characterized by a general loss of intellectual abilities involving impairment of memory, judgment and abstract thinking as well as changes in personality, I think, in reality, her case could also be said to address concerns about surrogate decision makers.
CHAPTER FOUR

4.0. RECENT CRITIQUES OF BEAUCHAMP AND CHILDRESS AND REACTION TO THE CRITICISMS.

The original framework containing four clusters of secular principles—*respect for autonomy, nonmaleficence, beneficence, and justice*—is upheld as "the common morality" accepted by "all morally serious persons." Often referred to as "the Georgetown mantra" (after Georgetown's Kennedy Institute of Ethics, where they were first drafted before publication in 1979), these principles have been widely accepted and have also been adapted in combination with other principles and concepts. However, the framework has also provoked controversy and questions about its adequacy to resolve critical issues in bioethics and in clinical practice. In response, Beauchamp and Childress have offered an extended defense of their theory and critical examination of points of debate. This is what I shall be dealing in this chapter.

4.1. CRITICISM FROM K. DANNER CLOUSER AND BERNARD GERT.

Danner Clouser and Bernard Gert argue that the ‘principles’ are not action guides at all, but that at most they represent a category of concerns, a listing of issues that should be considered in dealing with the problem in question. They went on to argue that the four principles are not systematically related to each other by any underlying unified theory. To buttress this point, they wrote,

> Of course each ‘principle’ is an expression of one or another important and traditional concern of morality. But there is no priority ranking; in fact, there is not even any specified procedure to be used in resolving particular cases of conflict between principles...Furthermore since they have neither foundations nor clear interrelationships, we believe they are useful primarily as a means of consciousness-raising, but not as a means of clarifying
Thus they find the ‘principles’ to be inadequate, and discussed in detail the principle of autonomy in order to demonstrate the force of their arguments. For them, the principle of autonomy (as well as beneficence), best illustrate the most problematic aspect of principlism.

One of their arguments against Autonomy is that the principle seems to be the centerpiece of the principlism. According to them, it is cited more frequently than the others and has really taken on a life of its own. According to them, this principle does not say merely that one should not constrain anyone’s actions and choices; rather it says that we should not constrain their autonomous actions and choices. The addition of ‘autonomous’, for them, is what causes most of the problems with the principle of autonomy.

From the point of view of action and choice, they argued that in practice, the basic difficulty with autonomy, is knowing whether or not the actions and choices one is concerned with are autonomous. It was on this regard that they wrote thus,

> In practice, the basic difficulty with autonomy, dogging it throughout all its uses, is knowing whether or not the actions and choices one is concerned with are autonomous Is the choice to give up drinking the autonomous choice or is the autonomous choice the choice to continue? Is the choice to withdraw from expensive life-prolonging treatment to save his family money and anguish the autonomous choice or is the autonomous choice to go on leaving a while longer? Which choice is it that we are being admonished not to constrain?2

This ambiguity according to them, invites a conflict between people who differ on which choice of the patient is the autonomous one. One side may favor

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overruling a patient refusal on the ground that the refusal is irrational, claiming that therefore the choice is not autonomous; whereas the other side may favor going along with the patient’s explicitly stated refusal on the ground that, though the refusal is irrational, the patient is competent and therefore the refusal is an autonomous choice. Both sides can claim that they are respecting the autonomous choice and, hence, acting on the principle of autonomy. They accused the principle of autonomy of being used to support two opposing ways of acting even when there is no disagreement on the observable facts of the case, and thus concluded that it is not a useful guide to action. Following the principle of autonomy for them may encourage one to act with unjustified paternalism; that is, to overrule the patient’s explicit refusal, simply because one views that choice as not being autonomous. Thus they said that the principle of autonomy might lead one to deprive a person of freedom without an adequate justification for doing so.

In another variation of their criticism, they argued that the principle of autonomy lacks a fundamental distinction of moral rules and moral ideals. Thus they argued,

\[\text{At the core of many problems with the principle of autonomy is its failure in practice (and the failure of principlism in general) to recognize the significance of the distinction between what is morally encouraged (following the moral ideals) and what is morally required (obeying the moral rules).}\]

According to them, appreciating this distinction within the moral system is basic and crucial.

Arguing from another perspective, they said that the principle of autonomy requires respect for autonomy, but it fails to distinguish between ‘respecting autonomy’ and ‘promoting autonomy’. They argue that since that crucial distinction was not made explicitly, the important difference between ‘promoting autonomy’ and ‘respecting autonomy’ is often neglected.

\[^3\text{ibid. , p.255.}\]
According to them, Beauchamp and Childress, after emphasizing and developing the intimate connection between autonomy and informed consent, state that they ‘accept the view that the primary function of informed consent is the protection and *promotion* of individual autonomy’. Thus if this are not distinguished, they argue that we will lose sight of the greater stringency of the former; not protecting (i.e. violating) autonomy is breaking a moral rule and thus requires adequate justification. On the contrary, they maintained that not promoting autonomy is not following a moral ideal and hence does not require justification. However, they agree that promoting autonomy may sometimes provide adequate justification for violating autonomy, but not distinguishing clearly between ‘protecting autonomy’ and ‘promoting autonomy’ inevitably leads to confusion.

The principle of autonomy, for them, embodies a deep and dangerous level of confusion; that which is created by unclarity as to what counts as autonomous actions and choices and the consequent blurring of a basic moral distinction between moral rules and moral ideas. They maintained that the introduction of the metaphysical concept of autonomy is unnecessary and inevitably results in making it more difficult to think clearly about moral problems. The goal of moral philosophy, they argued, is to clarify our moral thinking, not to introduce new and unnecessary complications.

### 4.2. **CRITICISM FROM THE NORDIC VIEW- HENRIK WULFF.**

According to the Danish physician Henrik R. Wulff, the Golden Rule is moral ideal within the health service in the Nordic countries. Wulff does not think that one can use Beauchamp and Childress’ bioethical principles as a tool for solving problems in the Nordic context because they do not correspond with the Golden Rule. It is on this view that Wulff write,

…the prevailing moral traditions in the Nordic regions are very similar. The moral codex to be extracted from this tradition is not the four principles in a particular ranking order, but the Golden Rule as it is formulated in the Sermon on the Mount: ‘And as ye
would that men should do to you, do ye also to them likewise’ (Luke iv. 31). This principle must not be taken to mean that we should attribute to others our own wishes and references, but rather that we should help others to pursue their happiness as we wish to pursue ours. The Golden Rule interpreted in this manner entails the idea of positive freedom.4

Wulff and other critics have pointed out that Beauchamp and Childress’ bioethical principles have appeared out of an American common sense, which is not necessarily shared with other cultures. Søren Holms’ writes,

Because the theory of PBE4 (Principle of Biomedical Ethics, 4th ed.) is developed from American common morality (and in reality only from a subset of that morality) it will mirror certain aspects of American society, and may, for this reason alone, be untransferable to other contexts and other societies.5

According to Wulff, from the American tradition one can deduce a morality based on the four bioethical theories in which the principle of respect for autonomy weighs the most while the principles of beneficence and of justice weigh the least. Contrary to this, Wulff thinks that the ethics embedded in the tradition of the Nordic countries is an ethics based on the Golden Rule. He writes that the moral codes that prevail in the North are based on the Golden Rule as formulated in the Bible. According to Wulff, reciprocal duties and a basic minimum of health care for all citizens play a major role in the Nordic countries.

According to Wulff’s theory, the principles of beneficence and justice weigh heavier in the North while the principle of respect for autonomy weighs heavier in the USA.

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4 ibid., p.280.
From this Wulff concludes that the four bioethical principles cannot be used in the Nordic countries, because they are arranged such that the principle of respect for autonomy comes first.

Wulff specifically criticises the principle of respect for autonomy. He writes that the formulation of this principle lacks stressing that the right to autonomy must be limited by humans’ fulfilment of positive duties towards others. He also specifically criticises the principle of beneficence. He writes that it concerns a one-sided obligation, that it is up to the individual to what extent(s) he will help others. Furthermore, he writes that the principle of justice is not especially informative, as nothing is written about what is to be understood by just treatment of others. He maintains that the interpretation of this principle depends on individual points of view, i.e. on one’s discretion.

Wulff concludes that Beauchamp and Childress paint a picture of an ideal for society in which the freedom of the individual is placed very high and where one only feels morally responsible for each other in a limited way, and thus accepts the existence of need and social injustice.

However, I think that Wulff misunderstood Beauchamp and Childress’ method. The four bioethical principles are defined as being coordinated. Which principle weighs the heaviest depends on the culture to which they are applied. I wonder why Wulff doesn’t use the primary text as a starting point because there the principles are defined as being coordinated.

When judging Beauchamp and Childress’ method one cannot look at one singular principle in isolation. The aspect that Wulff seeks from the principle of respect for autonomy is contained within the principle of beneficence. Again if one reads the primary text, then the principle of justice contains an egalitarian formulation of the principle and The Fair Opportunity Rule. This means that one cannot interpret the principle freely.
4.3. CRITICISM BASED ON LIMITATION.

R. H. Nicholson argues that the four principles might not after all be the last word in medical ethics. According to him, he is aware of the practical limitations of the four principles. Thus he writes,

Since then many more problems have become apparent to me, in addition to the absence of any coherent mechanism for resolving conflict between the principles. Some problems are inherent, some lie in the application of the principles. A philosopher could no doubt write at great length analyzing these problems, but that is not what seems to be needed here. I propose to discuss the problems polemically, rather than analytically, to show the limitations of the ‘Georgetown mantra’, as the four principles are now colloquially known.⁶

He says that the most basic limitation of the four principles is their aridity. He argues thus,

Perhaps the most basic limitation of the four principles is their aridity. They are reminiscent of the stony ground on which seed fell in the parable of the Sower. At first the corn sprang up, and then it withered because there was nothing to sustain it. The four principles are rationalist and derived from theory, with little to say to the complexity and joyful variety of real life.⁷

According to him, the principles have been only of temporary value, in providing a simple framework comprehensive to non-philosophers. He continued that one of the greatest dangers of the mantra is precisely that it has become ossified and formalistic, and is no longer viewed as just a step to further development.

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⁷ ibid., p.269
One of the more curious inherent problems, according to him lies in the apparent need to have separate principles of beneficence and nonmaleficence. He argues that it would seem at first sight, that the duties to beneficence or nonmaleficence were two sides of the same coin. How could one duty exist effectively without the other, he asked.

4.4. REACTION FROM TOM BEAUCHAMP AND JAMES CHILDRESS.

From the foregoing, we have seen that not everyone agrees that the four principles provide the best framework for health care ethics. Many have severely criticized the four principles approach as a ‘mantra of principles’, meaning that the principles have functioned for some adherents like a ritual incantation of norms repeated with little reflection or analysis. However, Beauchamp offers a counter-argument against the arguments that rejected the four principles approach.

Clouser and Gert brought the following accusations against the four principle system: (1) the ‘principles’ are little more than checklists or headings for list of values worth remembering, and so the principles have no deep moral substance and do not produce directive guidelines for moral conduct; (2) principle analyses fail to provide a theory of justification or a theory that ties the principles together so as to generate clear, coherent, specific rules, with the consequence that the principles and so-called derivative rule are ad hoc construction without systematic order; (3) these prima facie principles must often compete in difficult circumstances, yet the underlying account is unable to decide how to adjudicate the conflict in particular cases and unable theoretically to deal with a conflict of principles.8 Beauchamp and Childress wrote,

An important version of top-down theory (though not a pure deductivism) has been developed over the last four decades by Bernard Gert and his coauthors H. Danner Clouser and Charles

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Culver. When challenges arose to our framework of principles in the late-1980s, these authors emerged as our most unsparing critics. Clouser and Gert wrote several articles and part of a book to express concerns about prima facie principles. The coined the label “principlism” to refer to all accounts of ethics comprised of a plurality of potentially conflicting prima facie principles. They directed their criticism primarily at our framework of four principles and offered, as a substitute, a framework centered on rules.9

Responding to the criticism, Beauchamp says that he does not deny that the criticisms are important problems, worthy of the most careful and sustained reflection in moral theory. However, what he denies according to him, is that, Clouser and Gert or anyone else who uses either a principle-based or rule-based theory, (as Clouser and Gert does), have surmounted the very problems they list for their (Beauchamp and Childress’) four principles approach. According to him, the difference between what he and Childress call principles and what Clouser and Gert call rules is that their rule tend (as the point out) to have a more directive and specific content than their principles, thereby superficially seeming to give more guidance in the moral life. He pointed out that since their first edition (1979) they have always accepted specific rules, not merely principles, as essential in health care ethics, and that what they say about rules is noticeably similar to what Clouser and Gert say about rules, and with a similar content.

He made it clear that the principles they defend are not constructed with an eye to eliminate possible conflicts among the principles, because no system of guidelines could reasonably anticipate the full range of conflicts. No set of principles, he continued, or general guidelines can provide mechanical solution or definitive procedures for decision-making about moral problems in medicine. Experience and sound judgment are indispensable allies. He pointed

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out that the major difference between their theory and the Clouser and Gert’s approach has nothing to do with whether principles or rules are the primary normative guides in a theory, but rather with several aspects of their theory that he (Beauchamp), at least, would reject. Concerning these aspects of Clouser and Gert’s approach, he writes,

First, they assume that there is or at least can be what they call a ‘well developed unified theory’ that removes conflicting principles and consistently expresses the grounds of correct judgment-in effect, a canon of rules that expresses ‘unity and universality of morality’. They fault us heavily for believing that more than one kind of ethical theory can justify a moral belief. They insist that to avoid relativism there can only be ‘a single unified ethical theory’, and that there cannot be ‘several sources of final justification’. These are all claims I would reject…

James Childress in a brief defense proceeds by sketching and clarifying some presuppositions and implications of the principle of respect for autonomy in the light of several major criticisms. Concerning this, he made this assertion,

My brief defense will proceed by sketching and clarifying some presuppositions and implications of the PRA (principle of respect for autonomy) in light of several major criticisms. I will argue that many of those criticisms are misplaced because they are (perhaps deliberately) directed at some of the least defensible conceptions of the PRA. I will contend that an adequate conception of the PRA can meet the main criticisms leveled by various critics, whether communitarians, narrativists, virtue theorists, traditionalists or religionists.

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According to him, in several respects, the principle of respect for autonomy has been misunderstood and misinterpreted, in part as a result of flawed formulations and defenses by its supporters. As a result critics have found easier targets than they should have in particular formulations of the principle of respect for autonomy.

He argued that it has been mistaken to use the term ‘autonomy’ or even the phrase ‘principle of autonomy’. This is very evident in the use of the term by Clouser and Gert in their criticism. I must note here that in the third edition of *Principles of Biomedical Ethics*, Beauchamp and Childress reformulated what they had earlier called ‘the principle of autonomy’ as the principle of respect for autonomy. However, for Childress, this point is important because many critics seem to suppose that proponents of this principle have an ideal of personal autonomy and believe that we ought to be autonomous persons and make autonomous choices. He made it clear that the ideal of personal autonomy is neither a presupposition nor an implication of the principle of respect for personal autonomy, which obligates us to respect the autonomous choice and action of others.

Beauchamp and Childress concluded by saying that they do not deny that the problems Clouser and Gert deserve sustained reflection. However, they reject, certain assumptions that they make, especially their requirement that there be a single, clear, coherent, and comprehensive decision procedure for arriving at answers. According to them, they believe that the same criticisms Clouser and Gert direct at their account also affect their impartial rule theory.

4.5. **REACTION FROM RAANAN GILLON.**

Most people associate Raanan with his advocacy of the four principles. According to him, the four-principles approach has never purported to provide a decision mechanism or procedure for application when the principles conflict in a particular set of circumstances. He maintains that all they provide is a set

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of four prima facie moral principles, plus a concern for the scope of application of each, which anyone can accept as potentially relevant to his or her particular moral decisions. He pointed out that even though this may be dismissed with disdain as a ‘mere checklist’ of moral concerns, (as Clouser and Gert did) he maintained that a positive approach to such a checklist is preferable. It seems to him an outstanding moral significance if a common commitment to a ‘checklist’ of certain specific moral principles can be agreed which transcends barriers of religion, culture, politics, nationality, and philosophical stance, even gender. Thus he concluded that the criticism that the four principles are ‘mere checklist’ of potentially relevant moral concerns fails dismally.

Reacting to the criticism that the four principles fail to provide decision procedure in particular circumstances when the principles conflict, Raanan observes that the criticism is entirely accurate, but misdirected since the four principles were never claimed to provide such a decision procedure or procedures. Raanan’s offers a similar response to the criticism from Clouser and Gert that the four principles do not provide a coherent moral theory. Once again, he says that the criticism is perfectly accurate, but misdirected, for the four principles were never claimed to provide a moral theory, coherent or otherwise; it was only claimed for them that they are compatible with many different moral theories, themselves often mutually incompatible. According to him, the fact that the four principles do not comprise a moral theory but are compatible with most, if not all moral theories, is one of their most valuable features, for they offer a way of bypassing the deep and probably unresolvable conflicts between competing moral theories.

Concerning the criticism that the four principles is not applicable in other cultures and cases as buttressed by Wulff, Raanan remarks that the four principle can be harmonized differently in the same particular case, depending on the particular culture’s norms of harmony. Thus one culture may give greater ‘dominance’ to beneficence at the expense of say autonomy (for instance the Nordic culture), another may prefer the cool harmonies provided by the predominance of justice, and yet another culture may prefer the perhaps
more dissonant harmonies resulting from frequent predominance of respect for autonomy. He concluded that despite some assertions to the contrary, the four principles approach is neutral between the different cultural perspectives, provided only that the cultures take account of all the principles. Thus in very similar sets of particular circumstances, different cultures may ‘apply’ or ‘harmonize’ the same set of principles differently; consistently within the context of their own cultures, but inconsistently within the approaches of other cultures.
CHAPTER FIVE

5.0. EVALUATION AND CONCLUSION

5.1. EVALUATION.

So far, I have discussed variety of issues, terms, concepts, debates, etc, related to the principle of respect for autonomy. A systematic overview of it laid bare the important things we should know about autonomy, and most importantly the principle of respect for autonomy. I began by defining the concept of autonomy literally and in relation to applied health care ethics. This, I believe enhanced a systematic knowledge of the concept. The etymological definition, which literally means ‘self-rule’ or ‘self-determination’ assumed various shades of meaning in the modern time, precisely in applied health care ethics. Thus in the field of applied ethics, the term has been used with various technical meanings in different schools of ethics. In this field, we notice that autonomy has been distinguished from the principle of respect for autonomy. Gillon made an allusion to this when he said,

Autonomy must be distinguished from what is often known as the principle of autonomy, and which for clarity would be better known as the principle of respect for autonomy.¹

However, a historical view revealed that autonomy is not concept, as many would presume. Its historical background goes back to the ancient period, but was not so prominent in the medieval period. It first appeared in early Greek political philosophy, where it was used to indicate the independence of Greek city-states from outside control, probably from a conqueror, and their determination of their own laws.

From Graeco-Roman antiquity to our contemporary era, references have directly or indirectly been made to the concept of autonomy, but not in the same forms or methods as the case may be. Health care professionals, especially in health care ethics, have developed a number of frameworks within modern applied ethics. Respect for autonomy is an important moral principle in a number of these frameworks. In the four-principle approach developed by Tom Beauchamp and James Childress, and popularized in Europe by Ranaan Gillon, respect for autonomy is one of four basic moral principles together with nonmaleficence, beneficence, and justice.

Efforts to articulate some types of autonomy—‘autonomy of action’, ‘autonomy of will’, and ‘autonomy of thought’, respectively enhanced a deeper understanding of the concept of autonomy. It helped to buttress that patient whose voluntary muscles are paralyzed by curariforms but who is conscious because his anesthetist has forgotten the nitrous oxide and who tries in vain to devise a way of stopping the surgeon cutting him is perhaps a paradigm of a person whose autonomy of thought and will are active, but whose autonomy of action is temporarily completely absent.

In the proceedings of this work, it was made clear that there are other concepts and principles that cannot be dismissed with levity in the treatment of the principle of respect for autonomy. This gave room to understand that the principle of respect for autonomy is but only one out of a set of principles, which according to Beauchamp and Childress should function as an analytical framework that expresses the general values underlying rules in the common morality. Other principles in the framework are ‘the principle of nonmaleficence’, ‘the principle of beneficence’, and ‘the principle of justice’. Two other concepts of very great importance were discussed briefly, namely ‘paternalism’ and ‘surrogate decision-making’. It could be deduced from the brief discussion on these concepts that, as a "liberty-limiting" approach, paternalism is usually grounded in a theory of impairment: namely, that an individual lacks sufficient facts or mental capacity to make a sound choice. It was also made clear that the most important goal of informed consent is that
the patient has an opportunity to be an informed participant in his/her health care decisions.

Very important sections of this thesis were laid bare. Under this section, an investigation into the development of the four-principles approach by Beauchamp and Childress was carried out. After, this, attention was fully devoted to treating the principle of respect for autonomy only. It was made clear that this was not construed to consider respect for autonomy as a principle with priority over all other moral principles. Beauchamp and Childress made this point clear when they wrote,

We also maintain that construing respect for autonomy as a principle with priority over all other moral principles, rather than one principle in a framework of prima facie principles, gives it too much weight.²

It was made clear that why I chose to write only on this version was because health care professionals traditionally neglected this part of morality among others. Beauchamp and Childress’s structure of principles went beyond this tradition, by including the principle of respect for autonomy, among other parts of morality that traditionally have been neglected. In another variation of this section, a brief discussion on the role of the principle of respect for autonomy revealed that this role is better understood in the context of examining individuals’ decision-making in health care, especially informed consent and refusal. Thus informed consent also offers the clearest demonstration of the role of patient autonomy in medicine. The role of this principle raises variety of questions in applied health care ethics:

What is autonomy? Why should we respect autonomous choices?
Should respect for autonomy mean that a person can request assistance in ending his/her life? Does respect for autonomy mean that a patient can request treatment that the clinician does not think is in his/her best interests, or

² Tom L. Beauchamp and James F. Childress, Principles of Biomedical Ethics, (5th ed.), New York: Oxford University Press, 2001, p.104
treatment that is futile? Does it require us to consult them and obtain their consent before we do anything in the bid to help them? Who has the upper hand in decision-making? It is the physician or the patient? What is the intimate connection between autonomy and decision-making, especially when the conflicts and moral dilemmas in specific cases are so deep?

This ushered in an investigation into the intimate relation between autonomy and decision-making in health care ethics. This inevitable investigation covers the topic of the thesis. The intimate connection between autonomy and decision-making in applied health care, especially in various kinds of consent and refusal has taken center stage in medical ethics since the Salgo decision in 1957. Prior to that time, the physician’s supposedly moral duty to provide appropriate medical care typically surpassed the legal obligation to respect patient autonomy. The Salgo decision, however, concluded that physicians have a legal duty to provide facts necessary for the patient to make an informed decision. Thus, "the doctor knows best" long ago was replaced with "the doctor proposes; the patient disposes."

Although Beauchamp and Childress justified the obligation to solicit decisions from patients and potential research subjects by the principle of respect for autonomy, they however, acknowledged that the principle’s precise demands remain unsettled and open to interpretations and specification. While it is true that some writers in bioethics seem to affirm a duty of medical decision-making by patients, Beauchamp and Childress do not. Thus they wrote,

While it is true that some writers in bioethics seem to affirm a duty of medical decision-making by patients, we do not. We defend a

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3 The 1957 case “Salgo versus Leland Stanford Jr. University Board of Trustees”, involved a 55-year-old male with leg cramping and other symptoms of extensive arterial disease. The patient underwent translumbar aortograph by a surgeon. There was no apparent complication to the procedure, although the next morning the patient awoke paralyzed from the waste down. The patient claimed that his physicians had not warned him of the risk of paralysis.

4 Some of the writings of Robert Veatch and Haavi Morreim, for example, seem to suggest such an ideal or duty. See also Schneider’s analysis in his Practice of Autonomy.
principle of respect for autonomy with a correlative right to choose
(not a mandatory duty to choose).5

This investigation made it necessary to discuss issues like ‘surrogate decision-
making’, ‘the scope of application of the principle of respect for autonomy’
and ‘its application in relation with the three other principles’. Various forms
of the loss or absence of competency were considered to raise the issue of
surrogate decision-making. Decision-making for incompetent patients presents
itself as a troubling ethical problem. The underlying assumption that permits
surrogate decision-making in most countries is that incompetent patients have a
right to self-determination similar to that of competent patients. Reviewing the
scope of application of the principle of respect for autonomy, it became clear
that in complex societies such as those found in North America and Europe
patients from diverse ethnic, cultural, and religious backgrounds increasingly
confront health care professionals. This affects the relationship between
clinicians and patients to the extent that patients' deliberations upon the
proposed courses of treatment can, in various ways and to varying extents, be
influenced by their ethnic, cultural, and religious commitments. Obviously
only autonomous agents can fall within the scope of the principle of respect for
autonomy- one simply cannot respect the autonomy of a winter shoe or jacket,
nor of anything else that is not autonomous.

Since Beauchamp and Childress share the view that it is legitimate and
rewarding to diagnose cases through the lens of general ethical principles. It
was part of my duty in this thesis to outline some cases in health care ethics
that have generated a debate concerning the application of the principle of
respect for autonomy, precisely, the standard Jehovah witness case’, ‘the child
of a Jehovah witness case’, and ‘Helga Wanglie case’.

The discussion on the principle of respect for autonomy has also provoked
controversy and questions about its adequacy to resolve critical issues in
bioethics and in clinical practice. In response, Beauchamp and Childress have

5 Tom L. Beauchamp and James Childress, ibid, p.61.
offered an extended defense of their theory and critical examination of points of debate. Discussion on this featured major critics of Beauchamp and Childress, Danner Clouser and Bernard Gert, the Danish physician Henrik R. Wulff, and R. H. Nicholson. Clouser and Gert brought the following accusations against the four principle system: (1) the ‘principles’ are little more than checklists or headings for list of values worth remembering, and so the principles have no deep moral substance and do not produce directive guidelines for moral conduct; (2) principle analyses fail to provide a theory of justification or a theory that ties the principles together so as to generate clear, coherent, specific rules, with the consequence that the principles and so-called derivative rule are ad hoc construction without systematic order; (3) these prima facie principles must often compete in difficult circumstances, yet the underlying account is unable to decide how to adjudicate the conflict in particular cases and unable theoretically to deal with a conflict of principles.6 Wulff does not think that one can use Beauchamp and Childress’ bioethical principles as a tool for solving problems in the Nordic context because they do not correspond with the Golden Rule. Nicholson argues that the four principles might not after all be the last word in medical ethics. According to him, he is aware of the practical limitations of the four principles. He says that the most basic limitation of the four principles is their aridity.

However, Beauchamp offers a counter-argument against these arguments that rejected the four principles approach.

5.2. CONCLUSION.

I will start by pointing out that decision making in the field of bioethics has become increasingly complex. Contemporary biomedical ethics reflects theoretical conflicts of considerable complexity. Although a wide agreement that we can teach and practice biomedical ethics exist, there is, at the same time, divergent opinion regarding the methods for achieving these goals. Tom Beauchamp and James Childress use the term ‘principles’ to designate the most

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6 Ibid, p.388.
general normative standard of conduct and their set of principles was
developed specifically for biomedical ethics and was never presented as a
comprehensive ethical theory. Their central argument is that rules for health
care ethics can be formulated by reference to these four principles, alongside
with other moral considerations. Their choice of this set of moral principles as
the framework for moral decision-making in health care derives in part from
professional roles and traditions. The truism is that, for centuries, health
professionals’ obligations and virtues have been framed by professional
commitments to provide medical care, to protect patients from the harms of
disease, injury, and system failure, and to produce benefits that compensate for
any harms introduced. Through rules of nonmaleficence and beneficence, these
obligations have been expressed. Although Beauchamp and Childress built
their set of principles on this tradition, their own structure of principles,
however, goes beyond these commitments by their inclusion of parts of
morality that traditionally have been neglected, especially respect for
autonomy and justice.

However, since the principle of respect for autonomy and decision-making is
central to this thesis, I base my conclusion on them. I will here argue for the
moral principles of respect for autonomy (the obligation to respect the decision
making capacities of autonomous persons). Like Beauchamp, Childress and
Gillon, I take this principle to be a universally valid norm that warrants us in
making intercultural and cross-cultural judgments about moral depravity,
morally misguided beliefs, savage cruelty, and other moral failures. A recurrent
complaint about the four principles approach is that although in theory it claims
not to prioritise any one of the principles, in practice respect for autonomy
recurrently is prioritised. I don’t believe this is the truth. Beauchamp and
Childress also made the point clear when they said
We also maintain that construing respect for autonomy as a principle with priority over all other moral principles, rather than one principle in a framework of prima facie principles, gives it too much weight.\(^7\)

One of the common and perhaps misguided criticisms of the four principles is that they constitute a deductive system and therefore, presumably, a rigid method for arriving at conclusion to complex ethical dilemmas. But I want to point it right, that the principles are not a set of ordered rules with instructions for making inferences and arriving at deductive conclusions. As Gillion surmises, “the four principles approach does not provide a method for choosing.”\(^8\) I argue that it is misleading to suggest that those who engage in ethical theory can produce all relevant moral guidelines or crank out conclusions that immediately follow from principles. I rather maintain that, ethical theory, using principles invites us to reason through our moral dilemmas and offers some ways of doing so. I maintain also that the principle of respect for autonomy, together with the other principles do not presuppose a special religious, case, or Metaphysical base. Its interpretation depends on the case, culture, or religion. Which principle weighs the heaviest depends on the culture, case, etc, to which they are applied. Again, I would like to point out that, when judging Beauchamp and Childress’ method one cannot look at one singular principle in isolation.

Complex or problematic cases almost always involve contingent normative conflict, as do each of the cases treated in this thesis. However, I am in substantial agreement with Beauchamp that the first line of attack in managing these cases should be to specify the relevant norms in order to eradicate the conflicts among them. I will like to take our minds back, at this point, to the first and second cases treated in this thesis. It is concluded in the "standard" Jehovah’s Witness case that having autonomously chosen the authority of his religious institution, a Jehovah’s Witness has a reasonable basis on which to refuse a recommended blood transfusion. But the second case yielded a different conclusion. Thus in the case of the child of a Jehovah’s Witness, it is

\(^7\) Ibid, p.104.  
concluded that it is morally required—not merely permitted—to overrule this parental refusal of treatment. This goes a long way to show that styles of case analysis are legitimately diverse. Relevant norms and different goals of case analysis will direct a physician or a reader to identify specific elements in the cases as deserving of analytical development. There is no reason to suppose that the principle based approach supply the only way or special way to treat a case.

Regarding the intimate connection between autonomy and decision-making in applied health care, I am in agreement with Beauchamp and Childress. Based on this, I justified the obligation to solicit decisions from patients and potential research subjects by the principle of respect for autonomy, however, I must also acknowledged that the principle’s precise demands remain unsettled and open to interpretations and specification just as the cases buttresses. The conclusions I have reached here also apply to analogous contexts of surrogate decision-making that involve vulnerable and incompetent adult patients. A useful rule to restrict all surrogate decision making is this: If a designated surrogate makes a decision that threatens the patient’s best interests, the decision should be overridden unless there is an explicitly worded document executed by the incapacitated patient that supports the surrogate’s decision. Such a document requires that a once competent patient stated a treatment preference in an advance directive. There is no such document in Helga Wanglie’s case before us and therefore this exceptive rule does not apply. I am arguing that there is no relevant difference between the situations of a vulnerable child whose parents impose their religious views, as seen in the case of the child of a Jehovah’s Witness, and the situation of vulnerable adults whose surrogates impose their religious, etc, views. The conditions for autonomous choice must be distinguished from the ideal of autonomy. It is important for the moral life that people be competent, be informed, and act voluntarily.

Finally, one of the advantages of the four-principle approach is that it dismisses the view that there is a single ultimate principle of ethics. Thus
Beauchamp and Childress’s four principles approach rejects the view that there is a canon for bioethics, including a canon of four principles. In the four-principle approach, moral principles in their bare form as principles are little more than abstract rallying points for reflection. They four principles as well as rules such as ‘Don’t kill’ and ‘Tell the truth,’ do not give us much more information about how to lead our lives than such admonitions as ‘Be competent’ or ‘act virtuously’. They can be harmonized differently in the same particular case, depending on the particular culture’s norms of harmony. Thus one culture may give greater ‘dominance’ to beneficence at the expense of say autonomy (for instance the Nordic culture), another may prefer the cool harmonies provided by the predominance of justice, and yet another culture may prefer the perhaps more dissonant harmonies resulting from frequent predominance of respect for autonomy. I am in agreement with Raanan that despite some assertions to the contrary, the four principles approach is neutral between the different cultural perspectives, provided only that the cultures take account of all the principles. Thus in very similar sets of particular circumstances, different cultures may ‘apply’ or ‘harmonize’ the same set of principles differently; consistently within the context of their own cultures, but inconsistently within the approaches of other cultures.

In brief, the four principle approach claims that whatever your personal philosophy, politics, religion, moral theory or life stance, you will find no difficulty in committing yourself to four *prima facie* moral principles plus a concern for their scope of application.
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