

FACILITATING FEMINIST ETHICS CONSULTATIONS:
A LEGAL SOLUTION TO ENCOURAGE INNOVATIVE ETHICAL ANALYSIS

by

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STATEMENT BY AUTHOR

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ABSTRACT

This thesis aims to make feminist theory an integral part of hospital ethics committee (“HEC”) decisionmaking. Specifically, the feminist theories discussed in this thesis prioritize an awareness of social context. The small-scale study conducted for this thesis found that HECs already consider social context to some extent but that they may also be open to more systematic integration. As opposed to courts, HECs provide a space where innovative alternatives (e.g., feminist approaches) to principalist bioethical decisionmaking can be tested. In order to encourage the development of such alternatives, this thesis has proposed a framework for the relationship between courts and HECs so that patients can benefit from the strengths of both entities in ways that have not been possible in the past.

INTRODUCTION

Since the 1990s, most hospitals have formed committees to deal with difficult ethical issues that arise in the course of medical treatment.¹ Although there were hospital ethics committees (“HECs”) that formed in the early part of the twentieth century,² the majority of them were formed in the 1990s to satisfy the Joint Commission requirements for hospital accreditation.³ HECs are diverse in their membership but often include physicians, nurses, clergy, social workers, lawyers, and other community members.⁴ Their approaches to ethical decisionmaking are also diverse. It is evident that HECs have a strong role within the hospital when it comes to making end-of-life and other polarizing moral decisions. However, it is less clear how HECs inform or are informed by the U.S. judicial system (“the judiciary”) and to what extent academic bioethics⁵ shapes HEC practice. These ambiguities are important to explore because HECs, the judiciary, and academic bioethics have been interacting and influencing one another and will continue

¹ Glenn McGee et al., *A National Study of Ethics Committees*, 1 Am. J. Bioethics 60, 60 (2001).

² Susan M. Wolf, *Ethics Committees and Due Process: Nesting Rights in a Community of Caring*, 50 Md. L. Rev. 798, 798 (1991).

³ The Joint Commission is an independent not-for-profit organization that is acknowledged as the primary accreditation body for health care organizations in the United States. In 1992, the Joint Commission began requiring hospitals to have a system in place for dealing with ethical issues. McGee et al., *supra* n. 1, at 60. Today, this provision reads: “1. The hospital identifies ethical issues and issues prone to conflict. 2. The hospital develops a process to handle these ethical issues that are prone to conflict and implements a process when these issues* arise.” The Joint Commission, *Comprehensive Accreditation Manual for Hospitals: The Official Handbook*, RI.1.10 (Update 3, Aug. 2005) (Asterisk indicates a change became effective January 1, 2006).

⁴ McGee et al., *supra* n. 1, at 61, tbl. 2.

⁵ This thesis draws a line between the activities of hospital ethics committees and the activities of bioethics scholars. Bioethics scholars, who consider bioethical dilemmas outside of the clinical context, will be referred to as “academic bioethicists.” It is recognized, however, that some academic bioethicists have clinical applications in mind.

to do so. It is particularly important to explore the flexibility that has characterized HECs because they present a space where dominant approaches to health care decisionmaking can be challenged and innovative alternatives can be tested.

Specifically, HECs need an organized way to consider social context in clinical consultations. In considering social context it is important that HECs not only be aware of how patients, individually and collectively experience the health care system. It is also important for HECs to be aware of their own actions as they are constrained and facilitated by the health care system and academic bioethics. Factors such as gender, race, and class impact the way the health care system treats patients and these factors impact how individuals within the system interact with and perceive each other. If HECs fail to pay attention to the social complexities of the health care system, there is a great risk that individual patients' values, beliefs, and experiences will be set aside in order to satisfy the legal and bioethical traditions of privileging hegemonic "principles."

Evan G. DeRenzo and Michelle Strauss have begun to prioritize an analysis of social context with their feminist HEC consultation model.⁶ This model, which will be discussed in detail in Chapter One, provides a solid foundation for incorporating a feminist analysis of social context into the day-to-day operations of HECs. However, it is important to also consider obstacles that might prevent its implementation. In a world where bioethical dilemmas have gained increasing attention, due in large part to ever-changing medical technologies, patients and physicians no longer have the luxury of contemplating these dilemmas in a purely private setting. Instead, there are legal,

⁶ Evan G. DeRenzo & Michelle Strauss, A Feminist Model for Clinical Ethics Consultation: Increasing Attention to Context and Narrative, 9 HEC Forum 212 (1997).

political, and ethical influences that constrain the decisionmaking process for patients and physicians, influences that have contributed to HECs' proliferation. Because HECs owe their existence in part to these complexities, they must rise to the challenge and systematically consider how social forces shape ethics consultations for individual patients.

Feminist scholars have long explored the ways in which social forces shape individuals' experiences and knowledge. Because of this, feminist works are well suited to the task of guiding HECs in considering social forces as well. Specifically, the field of feminist bioethics is relevant to the problems addressed in this thesis because feminist bioethicists have already contributed to the literature on HECs and because some feminist bioethicists have challenged principlist bioethical theories. Feminist legal theory can also contribute to this thesis because it challenges the legal system to alter its often archaic practices, including adherence to hegemonic principlism.⁷ The work of feminist legal theorists is particularly important for addressing the intersection of HEC and judicial processes.

Hilde Lindemann Nelson asserts that feminist bioethicists have an important role in addressing new bioethical situations. In the past, feminists have challenged androcentric norms in bioethics and asked the crucial question: who is allowed to make

⁷ As will be discussed in detail in Chapter Two, principlism looks slightly different in the legal context than it does in the bioethical context, but its main premise is that "we" can devise or deduce principles from what we know about the law or what we know about varying expressions of morality that will help us solve any dilemma that is presented. The problem is that the "we" is usually one or more white, upper-class men who decide what the principles will be, to which problems the principles will apply, and how the principles will apply to a particular set of facts.

ethical decisions?⁸ In the past, the educated white male doctors who dominated the field addressed the ethical dilemmas presented in health care. Today, in a country where the personal has become very political in end-of-life decisionmaking, women and people of color are also involved in health care at every level. This thesis asks not only *who* is allowed to make ethical decisions, but *how* those ethical decisions are made within HECs, especially considering the constraints imposed by the legal system and dominant academic bioethics. In other words, how should HECs deal with a legal system that is increasingly involved in end-of-life decisionmaking and how should they contend with the very real possibility that individuals' values, beliefs, and experiences will be set aside in order to satisfy the legal and bioethics tradition of privileging hegemonic principles? Rather than simply assessing, questioning, and critiquing methods of ethical decisionmaking, however, Nelson insists that feminist bioethicists need to build bioethical theory in all areas of health care. Although this thesis does not attempt to directly contribute to bioethical theory, it does attempt to utilize some already-existing feminist theories to propose a reliable and equitable process that will allow HECs to contribute to bioethical decisionmaking in a way that attends to the lived experiences of all patients.

The nexus of legal, political, and ethical forces in health care decisionmaking becomes clear when an individual's unfortunate end-of-life circumstances become the subject of public scrutiny. The names Terri Schiavo, Nancy Cruzan, and Karen Ann Quinlan have become widely recognized because these women experienced tragic

⁸ Hilde Lindemann Nelson, *Feminist Bioethics: Where We've Been, Where We're Going*, 31 *Metaphilosophy* 492 (2000).

circumstances that forced their families, the medical community, the legal system, and the public to reassess the moral definitions of life and death.⁹ Most recently, scholars have scrutinized the circumstances of Schiavo's death and some have concluded that her life and death were used as a political tool to advance ultra-conservative religious agendas.¹⁰ The fervent attempts to preserve life at all costs gained some ground in Schiavo's case, where the U.S. Congress made it extremely clear that social forces can alter the course of decisionmaking for individuals.¹¹ Indeed, Congress gathered in an emergency session to pass a law specifically giving the Federal District Court for the Middle District of Florida jurisdiction to hear Schiavo's case and to give her parents standing to bring that case.¹² Similar controversies surrounded the situations of Cruzan and Quinlan and even after these women's eventual deaths, multiple and conflicting definitions of death remain.¹³ Because these cases received copious publicity and the intricacies of difficult end-of-life decisions for incompetent patients have consequently become familiar to many, if not most, people in the U.S., this thesis will rely on these circumstances to illustrate various points. However, it should be made clear that, for the purpose of this thesis, any other bioethical dilemma could be substituted in the place of an end-of-life example. For example, there may be a situation where the parents of a

⁹ Suzanne Rode, End-of-Life Decisionmaking for Patients in Persistent Vegetative States: A Comparative Analysis, 30 *Hastings Int'l & Comp. L. Rev.* 477 (2007).

¹⁰ George J. Annas, "I Want to Live": Medicine Betrayed by Ideology in the Political Debate over Terri Schiavo, 35 *Stetson L. Rev.* 49 (2005); Kathy L. Cerminara, Collateral Damage: The Aftermath of the Political Culture Wars in Schiavo, 29 *W. New Eng. L. Rev.* 279 (2007).

¹¹ Annas, *supra* n. 10.

¹² *Id.* at 58-60.

¹³ Jason L. Goldsmith, Wanted! Dead and/or Alive: Choosing Among the Not-So-Uniform Statutory Definitions of Death, 61 *U. Miami L. Rev.* 871 (2007).

person with mental impairment want to have her surgically sterilized to prevent pregnancy. An HEC might be called in to discuss the ethical ramifications of that procedure.

One goal of this thesis is to challenge HECs to purposefully consider the ways that gender, race, class and other social factors affect their clinical consultations and to resist the pressures to rely on hegemonic legal and bioethical principles. Another goal of this thesis is to challenge courts to integrate HECs into judicial end-of-life decisionmaking because HECs have the ability to attend to the lived experiences of all patients in ways that are currently inaccessible to the judiciary. To begin to fulfill these goals, Chapter One of this thesis will discuss the groundwork laid by DeRenzo and Strauss for the implementation of feminist HEC consultations. Then, the independent research conducted for the purposes of this thesis will build on the work of DeRenzo and Strauss, showing the extent to which HEC members utilize principles to inform their consultations and whether there is evidence that HEC members already implement feminist-type approaches to consultations. The findings of this inquiry will also set the stage for illuminating the obstacles facing HECs that wish to place more emphasis on social context in clinical consultations. Chapter Two explains the obstacles to implementation of an HEC consultation model like the one DeRenzo and Strauss have created. Specifically, Chapter Two describes how the primacy of legal and bioethical principlism threatens to ignore how social forces shape end-of-life decisionmaking. Finally, Chapter Three utilizes an existing legal standard to devise a plan for overcoming the obstacles faced by HECs. This thesis maintains that consideration of social context is

crucial for bioethical decisionmaking and that it is possible to implement such consideration in existing health care and judicial institutions through the unique location of HECs and the help of feminist scholarship.

CHAPTER ONE: HEC CONSULTATIONS AND CURRENT APPLICATIONS OF FEMINIST THEORY

I. A FEMINIST MODEL FOR HEC CONSULTATIONS

In 1997, DeRenzo and Strauss recognized the importance of integrating feminist theory into clinical consultation practice.¹⁴ They set forth a practical model for HECs to follow so that they could easily integrate an awareness of social context into their everyday operations. Recognizing that feminist theory is very broad and means many different things, they specified that their model relied on the theory of two feminist philosophers in particular: Virginia L. Warren¹⁵ and Seyla Benhabib.¹⁶ They relied on these works to design a model of bioethics that departs from but does not forsake traditional approaches. One of the authors' main concerns is that the traditional model of ranking principles and values tends to disregard the viewpoints of people who would rank the principles and values differently. However, they do not attempt to completely do away with traditional consultation models, but instead work within the traditional models by infusing academic feminist bioethics contributions into the current frameworks.

From Warren's work DeRenzo and Strauss gleaned the importance of recognizing that moral questions involve power relations and that "important features of the moral context are obscured by appeals for neutrality."¹⁷ They also highlighted that "attention to issues of inequality, relationships, and occupational roles have not typically been the

¹⁴ DeRenzo & Strauss, *supra* n. 6.

¹⁵ Virginia L. Warren, *Feminist Directions in Medical Ethics*, in *Feminist Perspectives in Medical Ethics* 32-45 (Helen Bequaert Holmes & Laura M. Purdy eds., Ind. U. Press 1992)

¹⁶ Seyla Benhabib, *Situating the Self* (Routledge 1992).

¹⁷ DeRenzo & Strauss, *supra* n. 6, at 214.

subject of moral concern.”¹⁸ After identifying these important points in Warren’s work, they apply them to their consultation model. In their model they require that questions (1) “be asked from different perspectives” (e.g., whether moral viewpoints are being overlooked); (2) that all aspects of a patient’s life are taken into account (e.g., psychological characteristics and socioeconomic status); and (3) that context is analyzed broadly (e.g., beyond the hospital bed).¹⁹

Benhabib’s work informed DeRenzo and Strauss’s model by reconceptualizing the concepts of universalizability and reversibility.

Universalizability is the requirement that moral prescriptions should be applicable to anyone in a similar situation. Reversibility is the requirement that we delimit self-interested decisionmaking by taking up other viewpoints. This is accomplished by omitting the details peculiar to our own perspective.²⁰

Benhabib suggests that these concepts should be applied to a “concrete other,” or a real person with a real life (i.e., the actual patient), rather than a “generalized other,” that would be an abstract version of a person who is representative of all people. The authors apply this to their model in three ways: (1) patients are moral actors who should have the benefit of an authentic conversation with other moral actors involved in the situation; (2) when the moral actors have authentic conversations they will learn things about each other that are important to the ethical decision; and (3) the moral agents involved are allowed to shape or question the moral conversation.²¹ Overall, DeRenzo and Strauss wanted HECs to implement three things: (1) “the taking up of other viewpoints”; (2)

¹⁸ *Id.* at 214.

¹⁹ *Id.* at 215.

²⁰ *Id.*

²¹ *Id.* at 216.

considering aspects of the patient's life outside the hospital, including psychological and socioeconomic factors; and (3) paying attention to "the context in which the problem has arisen." The "short form" of their model, intended for HECs' use in practice, can be found in Appendix A.

DeRenzo and Strauss's model begins to encompass the social context of HEC consultations but has the limitation that it seems to ignore or at least downplays any assessment of how HEC members are situated in the consultation. It asks the members to articulate the power dynamics and to identify the different values held by the different interested parties, but it does not stress that it is also important for the HEC members to include themselves in these assessments. Instead, the model could easily be implemented such that the HEC members play a supposedly "neutral" role in the consultation. This becomes particularly problematic when it is the HEC members' job, according to the model, to set forth the "ethically permissible options." If the HEC members are not candid about their own values there is the risk that what the patient views as an ethically permissible option will be left out. In this way, the model fails to move beyond the traditional principlism with which DeRenzo and Strauss are concerned. The detriments of reliance on bioethical principlism, which is bolstered by legal principlism, will be discussed in detail in Chapter Two.

Even though DeRenzo and Strauss have developed a consultation model that employs important feminist insights, the model has unfortunately failed to take hold in HEC practice in a systematic way since the article was published in 1997. Further research, outlined below, will show that individual HEC members may be thinking about

some of the important aspects of DeRenzo and Strauss's model, but these factors are not purposefully implemented in HECs.

II. AN INVESTIGATION OF HEC IMPLEMENTATION OF FEMINIST VERSUS TRADITIONAL BIOETHICAL APPROACHES

Eleven years after DeRenzo and Strauss published their feminist model for HEC consultations, it is necessary to assess whether feminist values are implemented either formally or informally in daily HEC operations. A small-scale investigation was conducted for the purposes of this thesis to determine whether HECs engage in a principlist approach to consultations, if they engage in a more contextualized analysis of a case, or if they combine the two in some way. As HECs become a more integral part of hospitals, and as technology makes it so that we have new and more complicated ethical dilemmas, HECs might resort to the offerings of traditional academic bioethics to satisfy institutional and legal pressures. There is the possibility that HECs do not or might not pay close attention to how the patients' values might be at odds with scholarly bioethical principles. Additionally, the investigation attempted to discover whether HEC members consider how their identities and the identities of the patients they serve might affect the consultation.

During the course of the investigation there were some minor obstacles. The study initially began as a comparative one wherein the chairpersons of three HECs would be interviewed and surveys would be handed out to the committee members of the same three committees. One HEC was located in a Catholic hospital, one was located in a private not-for-profit hospital, and one was located in a teaching hospital. Because of the lengthy process of obtaining human subjects research approval, combined with the

limited amount of time and resources involved in obtaining a master's degree, it was necessary to reduce the scope of the study. The downsized study, however, elicited valuable information about HECs consider the context of people's lives when they facilitate bioethical decisionmaking. The resulting study is discussed below.

A. Research Methods

This study consists of four sources of information: (1) an interview with the chairperson of an HEC at a private, not-for-profit hospital ("the interview" or "the chair"); (2) five published accounts of approaches to ethics consultation by current or former HEC members at various types of institutions ("accounts" or "published accounts"); (3) a survey of the members of the HEC at the same private, not-for-profit hospital where the interview was conducted; and (4) a published national survey of HEC practices. The data gathered in this study were analyzed with the aid of Amanda Coffey and Paul Atkinson's book, Making Sense of Qualitative Data: Complementary Research Strategies.²² Coffey and Atkinson suggest that coding qualitative data is a way to facilitate its analysis.²³ They provide examples of different methods of coding, but stress that the method of coding is not as important as the goal of reworking the data to find new analytical possibilities.²⁴ The method of coding the data in this study is inductive: discovering categories starting from the data rather than beginning with an established list of categories that will be applied to the data.²⁵ The goal of analysis in this study is to

²² Amanda Coffey & Paul Atkinson, *Making Sense of Qualitative Data: Complementary Research Strategies* (Sage Publications, Inc. 1996).

²³ Coffey & Atkinson, *supra* n., 22 at 26.

²⁴ *Id.* at 30.

²⁵ *Id.* at 31-32.

identify common themes across the interview, the surveys, and the published accounts to illuminate the extent to which HECs consider the effects of institutional and social factors on the ways in which different patients experience the health care system.

1. Interview and Published Accounts

The interview and published accounts have been combined in one category because they provide rich narratives about HEC approaches to decisionmaking. The interview was conducted in the office of the HEC chairperson, who is a physician at the same hospital. The interview was not recorded but notes were taken and organized on the same day as the interview. The goal of the interview was to gather information about the operation of the committee. More specifically, the interview intended to discover whether the HEC actively considers how institutional and social forces shape the experiences of patients. This information was obtained by asking about the training of new members and other practices of the committee. The full list of interview questions can be found in Appendix B. The interview was approved by the Human Subjects Protection Program at the University of Arizona as well as by the Institutional Review Board at the hospital where the interview occurred.²⁶

Five published accounts by current or former HEC members from around the country were selected for analysis because of their uniformity, as they were located in the same issue of the journal *HEC Forum* and the authors were asked to answer the same set of questions: (1) “What is your *educational and work background*? What strengths and weaknesses do you believe your background brings to the clinical consultation

²⁶ In order to protect the anonymity of the study participants, the hospital will not be identified in this thesis.

experience?” (2) “What are the *mission and core values of the institution* in which your clinical consults are conducted? How do these institutional commitments affect the clinical consultation process, if at all?” (3) “What do you think is the *ideal way to integrate your own personal values and commitments* into the consulting process?”²⁷

These questions most closely aligned with the goals of this study and therefore provided a systematic and relevant look at HECs across the country and in different types of institutions. The purpose of analyzing the published accounts is to provide context for the results of the interview and the survey data, providing a broader look at HECs’ attention to institutional and social forces. In order to adhere to a structured method of analysis, the accounts were first reviewed for answers to the same questions asked in the interview with the HEC chairperson and in the open-ended survey questions discussed below. Then, the interview, the published accounts, and the open-ended survey questions were coded.

As mentioned above, coding of the interview and published accounts was inductive, meaning that categories were discovered from the data.²⁸ The purpose of the coding was to rework the data and think about it in different ways. In other words, the coding expanded the possible conclusions about the research rather than narrowing it.²⁹ The coding took the form of identifying key words in the answers to the interview and open-ended survey questions and then aggregating them to find common themes. Then

²⁷ James M. Dubois, *Editor’s Introduction: The Varieties of Clinical Consulting Experience*, 15 HEC Forum 303, 304 (2003) (emphasis in original).

²⁸ Coffey & Atkinson, *supra* n. 22, at 32.

²⁹ *Id.* at 29.

the themes were utilized in reevaluating the original answers to the questions.³⁰ The resulting themes will be discussed in the data analysis section, below.

2. Surveys

The survey was handed out to the HEC members at a monthly meeting of the HEC. Five committee members out of the eleven present at the meeting returned the survey by mail.³¹ The survey consisted of 22 closed-ended Likert-scale questions and two open-ended questions. The purpose of the survey was to determine if HEC members are independently thinking about how institutional and social forces shape the experiences of patients, including their own role within the institution. The Likert-scale answers were entered into an excel spreadsheet for ease of making comparisons between the surveys. The survey questions are provided in Appendix C.³² Because of the small scale of this study, the survey is meant to provide a glimpse into the minds of HEC members as qualitative data rather than as quantitative data. Therefore, the surveys are analyzed as a way to expand the view of a particular HEC without suggesting that these HEC members are more broadly representative of HEC members nationally or even locally. Additionally, the open-ended questions are combined with the interview and published accounts data to further illuminate the decisionmaking processes of HECs. As with the interview, the survey was approved by the Human Subjects Protection Program

³⁰ *Id.* at 49.

³¹ The HEC chair requested that the surveys be returned by mail so as not to take up time during the HEC meeting.

³² Due to the small number of study participants and the need to protect anonymity, the excel spreadsheet will not be provided in this thesis.

at the University of Arizona and by the Institutional Review Board at the hospital where the survey was administered.

3. National Study

Finally, there has been one major national study investigating the practices of HECs. The national study provides little insight into the major questions of this study but is referenced here to provide background about the functioning and member profiles of HECs on a larger scale than can be determined by the current study.

B. Data Analysis

This section provides the general impressions and themes gained from an analysis of the above data sources. This synopsis is combined with suggestions for further exploration and foreshadows the arguments made in subsequent chapters.

1. Interview and Published Accounts

a. *HEC Members' Personal Approaches to Consultation*

The data indicate that HEC members generally see themselves as intermediaries whose job is to listen, interpret, and mediate the health care decisionmaking process. Although each committee is run differently and each of the committee members comes from a different background, this is probably the most generalizing statement that can be made about how HEC members begin to approach consultations. Most members do not see themselves as decisionmakers but instead as decision facilitators. For instance, one of the published accounts indicates that “[t]he ethics consultant’s unique function is to

interpret the meaning and implications of the patient's values for medical decision-making and to assist surrogate decision makers to accommodate those values."³³

Some members intentionally consider the social context of bioethical dilemmas presented in consultations. For instance, they indicate that factors such as the patient's culture and ethnicity are important for analyzing a bioethical dilemma. Another stressed the importance of taking a holistic view of the patient and the circumstances.³⁴ Not only are HEC members thinking about the patients in this way, but some members also find it important to pay attention to how their own values and cultural influences affect the consultation process. In response to a question asking HEC members' to describe their personal approaches to consultations, one HEC member wrote: "[I] consider how *my* values and cultural approaches interpret the circumstances." Because some HEC members already think about how social factors affect health care decisionmaking, this suggests that they may be open to the idea of considering these factors in a more organized and constructive way.

Some HEC members also consider how religion is implicated in the bioethical dilemma. It is important to assess how the patient's religious beliefs would affect the decision if the patient were competent to make the decisions for herself. It is also important to consider how HEC members' religious beliefs affect the HEC members' approaches to consultations. Additionally, in a religious hospital, it is important to assess how the religious affiliation of the institution informs the HEC consultations and what the

³³ George J. Agich, *Joining the Team: Ethics Consultation at the Cleveland Clinic*, 15 HEC Forum 310, 318 (2003).

³⁴ Patricia Talone, *Catholic Health Care Ethics Consultation: A Community of Care*, 15 HEC Forum 323, 328 (2003).

HEC members' commitments are for upholding the hospital's religious mandates. These settings raise many questions about how institutional and HEC member religious commitments might be at odds with the patients' religious beliefs and how this impacts decisionmaking.³⁵

b. *Formal Bioethical Theory Informing HEC Members*

Of the surveyed members, only one indicated that she relied on any sort of formal bioethical theory; she indicated that the sanctity of human life and autonomy are principles guiding her in consultations. The HEC chair indicated that no one on the committee had any formal training in bioethics and the survey confirmed that report. The chair also reported that sometimes an ethics consultant might attend a meeting to help the committee think through issues but that this probably did not make any difference in the outcome of the decisions.

The published accounts reflected a higher incidence of formal bioethics training; in fact, the authors were probably selected to publish their accounts because of this training. The most often cited source of formal training was religious in nature.³⁶ The Ethical and Religious Directives for Catholic Health Care Services were specifically cited,³⁷ as was Orthodox Christianity.³⁸ The only specific secular source of formal bioethics cited was the Core Competencies for the Health Care Ethics Consultation

³⁵ The role of religious beliefs in bioethical decisionmaking is important but a thorough discussion of the related issues exceeds the scope of this thesis. Instead, religious beliefs will be generally considered along with other social factors such as gender, race, and class. For a comparison of HEC consultations in secular and religious institutions see Orr.

³⁶ Talone, *supra* n. 34; H. Tristram Engelhardt, Jr., *The Bioethics Consultant: Giving Moral Advice in the Midst of Moral Controversy*, 15 HEC Forum 362 (2003); Robert D. Orr, *Pilgrimage and Profession*, 15 HEC Forum 352 (2003).

³⁷ Talone, *supra* n. 34, at 326.

³⁸ Englehardt, *supra* n. 36, at 372.

provided by the American Society for Bioethics and Humanities.³⁹ “Principles” were cited generally but were not discussed in enough detail to really illuminate what was meant by the term.⁴⁰ For example, one published account related that “[t]he distinctive character of clinical bioethics consultation creates its own process...blending ethical principles and mediation skills into something unique.”⁴¹ Another account alluded to the principles espoused by Beauchamp and Childress, which are discussed in more detail in Chapter Two: “The ethical principles at stake [in the described consultation] were clear. Primary among these was non-maleficence.”⁴²

Finally, formal bioethics knowledge came from the study of philosophy,⁴³ from bioethics fellowships,⁴⁴ and from full-time employment as a clinical bioethicist.⁴⁵ Once again, however, there was no explicit or implicit reference to specific bioethical theories.

c. *The Consultation Process*

There is a theme of collaboration and consensus in the consultation process. In other words, HEC members value working with all the parties interested in the particular consultation, including physicians, nurses, patients, patients’ families, and other HEC members. Additionally, collaboration with people representing diverse disciplines in considering bioethical dilemmas was also indicated as important. The goal of collaboration seems to be the reaching of a consensus on the particular bioethical

³⁹ Talone, *supra* n. 34, at 333.

⁴⁰ Talone, *supra* n. 34; Linda Farber Post, *Clinical Consulting: The Search for Resolution at the Intersection of Medicine, Law, and Ethics*, 15 HEC Forum 338 (2003).

⁴¹ Post, *supra* n. 40, at 346.

⁴² Talone, *supra* n. 34, at 330.

⁴³ Englehardt, *supra* n. 36.

⁴⁴ Post, *supra* n. 40.

⁴⁵ *Id.*

dilemma at hand. In fact, one published account stated that “[t]he strong collegial and collaborative character of the Cleveland Clinic supports ethics consultation.”⁴⁶ The references to collaboration and collegiality refer to relationships with health care professionals as well as patients and families. The value placed on consensus would suggest that the HEC is not engaged in picking sides or playing favorites, so to speak. Rather, as indicated in Section 1(a), above, HEC members see themselves as intermediaries. However, there is also some indication that the role goes beyond that of an intermediary. For example, the HEC chair indicated that the HEC talks to the patient and family members until they understand the patient’s situation and one published account mentioned clarification as part of the process: “Clarifying decisional priority as defined by law and custom...can effectively manage disagreements and uncertainties.”⁴⁷

It is important for HECs to be careful about drawing the line between clarification and persuasion. It may be that the patient or the family members do not understand the patient’s medical condition or the available options for treatment or non-treatment. However, it is also possible that the patient or family members do understand the options and wish to make a decision that is at odds with the health care professionals’ viewpoints. In fact, that decision may also be at odds with “custom.” This type of dissonance, however, does not mean the decision is automatically bad. Although it seems like a laudable goal to clarify “custom,” it is unclear from this study whose customs are followed and how much the varying parties must compromise their values to reach a “consensus.”

⁴⁶ Agich, *supra* n. 33, at 317.

⁴⁷ *Id.*

Identification of relevant bioethical principles was mentioned as another important part of the consultation process. As mentioned above, the published accounts were unclear as to which principles are utilized to frame various situations. The following quote further describes the lack of clarity relating to principles in the published accounts: "...we use as our analytic framework the notion of 'principled resolution...a plan that falls within clearly accepted ethical principles, legal stipulations, and moral rules defined by legislatures, courts, and ethical discourse....'"⁴⁸ The accounts lacked clarification as to how the principles would be used and what the effect the use of principles might have on patients, including how the principles might conflict with the patient's values and whether the use of principles "narrows the options"⁴⁹ in a way that is helpful or hurtful to the patient. It is likely that further discussion with the authors of the published accounts would shed light on the specific principlist approach used. The bottom line is that the authors have made clear that principles are used in guiding consultations.

Gathering information is another part of the consultation process and some of that information may be related to social context. Some members were interested in learning about the patient's family, religion, culture, and history as they gathered information needed to make recommendations or facilitate communication. One published account said: "One must also see the patient in a broader, wholistic sense, learning...relevant information about his or her family, religious beliefs, culture, history, etc."⁵⁰ It is unclear

⁴⁸ Post, *supra* n. 40, at 348 (second ellipsis in original) (citing n. 8).

⁴⁹ *Id.* at 347.

⁵⁰ Talone, *supra* n. 34, at 328.

what constitutes the “etc.” in the sentence, but perhaps there is room for attention to gender, race, and class inquiries and insights. It would be useful for HECs to also take one step further and think about how to use information about social context in an organized way and to be purposeful about what information is gathered so that it can be used in a way that best illuminates patients’ situations.

d. *HEC Responsibilities*

The study identified several HEC responsibilities. The most emphasized responsibility is education. HECs also indicated that identifying issues involved in a particular bioethical dilemma is an important part of their work. It was also suggested that it is the responsibility of HECs to narrow the decisionmaking options to those that are morally acceptable. After education, the most often cited responsibility is to facilitate communication between various decisionmakers and interested parties. Finally, there is some indication that making the HEC members’ partialities explicit to the interested parties is important for carrying out the HEC’s tasks responsibly.

Education is an important responsibility of HECs. Education takes many forms. For instance, HECs educate patients about particular moral dilemmas. They also educate health care providers about how to effectively deal with ethical issues without the help of HECs. One account relates:

The Ethics Liaison Services are designed to enable and empower physicians and other healthcare professionals to address ethical questions and problems as they arise in the course of patient care without a formal ethics consultation.⁵¹

⁵¹ Agich, *supra* n. 33, at 316.

Additionally, they sometimes work to merely educate people about how to contact and utilize their services. Finally, they spend some time educating the institutional leaders, the community at large, and themselves about various issues. Another published account prioritized education: “In my opinion, it is almost impossible to over-emphasize the importance of ethics education within health care institutions and systems.”⁵²

Identification of issues relevant to the particular patient is another responsibility of HECs. One published account proffered that ethics consultants should privilege “cognitive values.”⁵³ Cognitive values “include thoroughness in the assessment of the problem and circumstances from which the request for consultations arises, and interpretation of institutional policies, professional consensus guidelines, applicable law, and relevant literature.”⁵⁴ Presumably all of these resources will aid the HEC in identifying relevant ethical considerations.

Narrowing the range of options to those that are ethically permissible is a responsibility identified by one published account. This particular responsibility is similar to one routinely seen in the physician-patient relationship: “Guiding option discrimination is similar to the clinician’s obligation to engage patients and families in considering only “real choices,” those therapeutic options with genuine alternatives that permit genuine decisionmaking.”⁵⁵ While it may be necessary to eliminate some “options” due to their unethical or illegal nature, this is a point where HECs should be

⁵² Talone, *supra* n. 34, at 333.

⁵³ Agich, *supra* n. 33, at 318.

⁵⁴ *Id.*

⁵⁵ Post, *supra* n. 40, at 347.

careful not to eliminate choices about which there may be legitimate disagreement and a family's alternative choice would still fall within the bounds of ethical decisionmaking.

Facilitating communication between interested parties is another HEC responsibility. HECs approach this task in a variety of ways. One approach is through mediation. "Mediation presupposes that the parties either begin on or can be helped to achieve a relatively equal standing of knowledge and power."⁵⁶ The HEC chair indicated that his committee is considering a move toward this type of consultation model.

Another approach to facilitating communication between interested parties is through what one account describes as "consultation."⁵⁷ This type of approach entails the HEC taking on the role of ethics expert where the goal is to make a recommendation or decision rather than merely helping others to come up with a solution. Finally, another account describes the narrative approach, where the analysis begins with and focuses on the patient. A narrative approach "...put[s] the patient first, recognizing that the medical analysis has meaning only in light of this particular person at this point in time. It also situates the individual within a context."⁵⁸ This is merely a quick description of some possible approaches. An HEC might employ different approaches in different situations or a combination of approaches.

In considering the responsibility of facilitating communication, it is necessary for the HEC members to be aware of their own partiality so that some of the concerns brought forth in the data can be dealt with openly. For example, it may be difficult for

⁵⁶ *Id.* at 347.

⁵⁷ *Id.* (citing n. 8).

⁵⁸ Talone, *supra* n. 34, at 330-331.

families and physicians to see the difference between HEC members as intermediaries and HEC members as ethics experts with definitive answers. According to the one account, the latter is not desirable: "...the opinions of a bioethics consultant may be taken to be an official deliverance regarding the binding morality that ought to be accepted by all rational persons."⁵⁹

Making their own partialities explicit may already be recognized as a responsibility of HEC members. One account explains that "[r]ather than artificial impartiality, the key to authentic facilitation is transparency. While the consultant should not advocate for any party or position, the ethical reasoning that informs the process should be available."⁶⁰ Although the account does not explicitly describe how ethical reasoning is made available, the author seems to suggest that this information is part of the discussions with various decisionmakers. It was also suggested that HEC members must be careful not to be mistaken for moral/ethical experts with all the right answers, because it may be tempting to both patients and health care workers to see them as such inadvertently. Instead, "...bioethics consultants should not only aid others in being clear regarding their moral views; bioethics consultants should also be clear about and disclose their own moral views."⁶¹ The focus on making partiality explicit was limited to moral positioning alone and not other types of partialities such as those that might be tied to the HEC members' experience of gender or race in the health care system, partialities that may be equally as important as explicit moral positioning.

⁵⁹ Englehardt, *supra* n. 36, at 371.

⁶⁰ Post, *supra* n. 40, at 348.

⁶¹ Englehardt, *supra* n. 36, at 377.

e. *HEC Member Training Focused on Gender, Race, and Class*

There was no discussion of the training that new or continuing HEC members receive in any area, except that the HEC chair indicated that there are retreats where there might occasionally be an educational portion on a particular topic. Time at the retreats is mostly reserved for discussing the HEC's operations, such as how to recruit new members and how to let the hospital staff know of the HEC's existence. Training for new members is an opportune space where HEC members can discuss their own positions in the consultation and how their own race, gender, and class positions affect how the patients perceive them and how they perceive the patients. Retreats and monthly meetings provide another ideal space for this type of discussion.

At least some HECs actively consider economic class when they conduct consultations. For instance, one published account made clear that Catholic hospitals must uphold their commitment to the poor: "...realizing the intimate connection between poverty and inadequate health care..., the bishops urge Catholic facilities to commit to care for the poor in concrete action at all levels of health care."⁶² Therefore, if class is an important consideration in Catholic hospitals and in Catholic conceptions of bioethics, then it must also be an important consideration for HECs operating within Catholic hospitals. It is not clear whether this emphasis on serving the poor is conveyed in a formal way to new HEC members or if it is learned in an informal setting. It is also possible that some HEC members would not be aware of this emphasis on serving the poor. There was no evidence of this same type of emphasis on the poor gathered from

⁶² Talone, *supra* n. 34, at 327.

the other types of institutions examined in this study (e.g., secular, not-for-profit). Once again, attention to other factors such as gender and race is not identified in this study.

f. *Identities of HEC Members*

The published accounts mentioned partiality, background, and moral diversity as affecting HEC consultations in general but did not connect specifically to the factors of race, class, and gender. The interview with the HEC chair elicited the response that, in the chair's opinion, race, gender and class do influence the way members make decisions but he was unable to point to evidence of this influence. Also, the chair asserted that professional status of the members probably overrides the other factors. For instance, medical training might influence doctors' perceptions of a bioethical dilemma more than race or gender.

g. *Importance of Having Diverse HECs*

There is no indication in the data that HECs attempt to create diversity along the lines of race, gender, or class when selecting members. The HEC chair said that a lack of HEC resources prevents the use of any selection criteria of members because anyone who wants to become involved is welcome. There is also no indication that there is an attempt to recruit particular members (e.g., women, community members representing the racial make-up of the community). It is unknown to what extent having a diverse HEC might affect the consultation process, but it might have the effect of shedding light on how different people experience the health care system because it would provide a diversity of perspectives. However, a different type of diversity, multidisciplinary, was deemed important: "In many ways, my consulting supports the argument that the strength and

utility of clinical ethics come not from specialization, but from the integration of knowledge and skills from many disciplines and perspectives.”⁶³

h. *HECs’ Influence Within the Hospital*

Education surfaced as a common way for HECs to have some influence within the hospital. The educational influence the HEC has within the hospital parallels HECs’ responsibilities for education. HECs educate patients about particular moral dilemmas; they educate health care providers about how to effectively deal with ethical issues without the help of HECs; they work to inform hospital employees and patients about how to contact and utilize their services; and they spend time educating the institutional leaders, the community at large, and themselves about various issues. One account noted: “...successful consultations are also educational models that provide clinicians with knowledge and skills that can be applied in future cases that raise similar issues.”⁶⁴

Aiding the institution in reaching its goals was also identified as part of HECs’ influence within the hospital. This varied from upholding and/or facilitating the institution’s goals to providing a risk management function. For example:

...[T]he bioethics consultant functions on behalf of physicians and health care institutions as a specialized service manager who aims at ensuring patient and family satisfaction and at mediating conflicts of authority and emotion among physicians, nurses, and other caregivers, thus assisting service delivery by hospitals.⁶⁵

As an entity that supports institutional goals, the HEC should have some insight into how institutional goals shape patients’ and families’ experiences within the institution. This

⁶³ Post, *supra* n. 40, at 344.

⁶⁴ *Id.* at 349.

⁶⁵ Englehardt, *supra* n. 36, at 370.

insight could easily become part of HECs' educational responsibility so that HECs teach health care professionals, patients, and families about institutional influences and how those impact a particular ethical dilemma. Discussing and analyzing interactions with the institution could also be more formally integrated into educational programs for HEC members.

Some HECs have very little power in the institutions where they are located. The HEC chair indicated that the HEC had very little influence within the hospital and that it was a struggle to merely educate the health care professionals in the hospital about their existence and how to utilize the HEC's services. It is clear that HECs are constructed and utilized in a variety of ways. Some HECs, like the one that was the subject of the interview in this study, may have more goals than influence. Other HECs are more established and have more financial resources and therefore may be more influential simply because they have the means to advertise more and conduct more consultations. Even though the HEC chair in this study indicated a low level of influence, the HEC has the goal of increasing its influence through education of hospital staff and assessing operational strategies (e.g., whether to provide consultation or mediation). However, the HEC in this study is comprised of volunteers who must be willing to take on more time-consuming roles if education is increased.

Just as HECs have an influence in hospitals, hospitals also have an influence on HECs. One published account related that a hospital's culture shapes the HEC's culture.⁶⁶ For example, one Catholic Hospital's focus on promoting the "common good"

⁶⁶ Talone, *supra* n. 34, at 327.

shapes the way the HEC in that hospital approaches consultations.⁶⁷ One way the “common good” shapes the ethics consultation is through the abandonment of individualism in the conceptualization of health:

By grounding the ethicist within a community of believers, the bishops’ directives, and particularly the normative principles, serve as an antidote to the individualism that haunts American culture and presses our health care system to the breaking point.⁶⁸

Understanding how hospital culture and HEC culture interact can contextualize HEC members’ roles within the institution and in the larger health care system. The example of the “common good” reveals that there are larger forces that shape the actions of HECs and that it is important for HEC members to be aware of those forces. In this particular example, HEC members should be aware of how a strong sense of individualism in the United States might be at odds with the Catholic “common good” or other similar conceptions of delivering health care.

i. *HECs’ Obstacles*

The conflation of ethical advice with legal advice was identified in this study as one of the most prominent obstacles for carrying out effective HEC consultations. For instance, a physician might rely on a consultation with the HEC as an indication that the ethical path was also the path that would help prevent legal liability.⁶⁹ Alternatively, a patient’s family might view the HEC’s recommendation as the only path because they see the HEC as an ethical authority. This obstacle indicates that whether or not formal bioethical theories are utilized by HECs, there is some amount of power that accompanies

⁶⁷ Id.

⁶⁸ Id.

⁶⁹ Englehardt, *supra* n. 36, at 371.

the intermediary role of ethics consultants. It is therefore paramount that HECs responsibly approach the decisionmaking process. Part of this responsibility is considering social factors such as the effects of race, gender, and class on patients' experiences of the health care system.

Difficulty recruiting HEC members, advertising the committee's existence, and gaining trust were identified as obstacles related to the basic functioning of HECs. One published account, for example, highlights that gaining the trust of all the parties involved is crucial for effective case consultation:

I learned that my effectiveness as an ethics consultant was directly related to the trust and confidence that I earned with the patients, families, physicians, nurses, and other health care professionals. Taking extra time or making the extra effort to follow up on the concerns of nurses, for example, proved to be an invaluable tool for gaining widespread acceptance within the institution.⁷⁰

Through an understanding of the social (e.g., institutional, legal) constraints on the various parties involved in a particular bioethical dilemma, HEC members will be able to better communicate with those parties. It is likely that this increased understanding of constraints followed by improved communication will also result in heightened trust and confidence in the role of HEC members in the decisionmaking process.

2. Surveys

The survey found that committee members seem to think, generally, that the race, gender and class of patients make a difference in health care decisionmaking. Class was the biggest factor for the surveyed members. Perhaps this is because class is more tangible to the committee members than race or sex in its relation to the health care

⁷⁰ Agich, *supra* n. 33, at 314.

system. It is clear that in this country if you are poor and/or uninsured, your health will suffer.⁷¹ The influence of race and gender are subtler in this system but just as important to consider.⁷²

The survey also indicated that committee members were less inclined to believe that their own race and gender affected their approach to the consultations. However, it was clear that they felt their occupations affected their analysis of ethical dilemmas in consultations. The occupations of the surveyed members included two physicians, two social workers, and a nurse/administrator.

The survey data were split as to whether maintaining neutrality was possible or desirable. HEC members should be actively aware of their stance on neutrality because patients, families, and others involved should know how each HEC member approaches the consultation. One reason this is important is because decisionmakers may conflate HEC recommendations with legal or institutional rules, leading them to believe the recommendations possess greater significance than they actually do. The issue of neutrality should be addressed in the training or continuing education of HEC members. Because this thesis takes the position that neutrality is impossible, it also asserts that attempting to maintain the façade of neutrality without being explicit about one's position can be harmful to patients. This point will be discussed in Chapter Two.

⁷¹ See e.g., Joseph S. Ross, Elizabeth H. Bradley, & Susan H. Busch, Use of Health Care Services by Lower Income and Higher Income Uninsured Adults, 295 JAMA 2027 (2006).

⁷² See e.g., Richard G. Roetzheim et al., *Effects of Health Insurance and Race on Early Detection of Cancer*, 91 J. Natl. Cancer Inst. 1409 (1999) (finding that insurance coverage, education, and socioeconomic status do not account for racial differences in diagnosis of cancer and that black patients were diagnosed with breast and prostate cancer at later stages than white patients).

3. National Study

The quantitative national study of HECs by McGee et al. addresses and supports some of the data collected in this study.⁷³ First, the study found that approximately 65 percent of HECs' time is spent on consultation, self-education, and retrospective review of cases.⁷⁴ This is consistent with the reports that education is an important component of HEC functioning. The other time was spent on hospital policy-making, verifying the accounts of HECs as engaged in supporting the institution's goals and operations.⁷⁵

Along with policy making, the study also found that some HECs are involved in the institutions' financial matters, serving as either part of the risk management team or by saving money for hospitals and patients as a byproduct of their services.⁷⁶ These functions are consistent with the data from the published accounts. If HECs are involved in this sort of activity, it becomes even more important for them to be explicit about their partialities because institutional finances are very likely at odds with unfettered delivery of health care to patients. For example, it is much more cost effective to terminate life support than to sustain a patient's life indefinitely, but the most ethical course of treatment may be to keep the patient on life support.

The study identified several outcomes of consultations, including the issuance of recommendations (95%) or binding decisions (5%), facilitating health care professionals' communication with families (73%), and providing consultations to risk management teams (39%). Additionally, the remarkable variations in HEC function "can be accounted

⁷³ McGee et al., *supra* n. 1.

⁷⁴ *Id.* at 61 tbl. 3.

⁷⁵ *Id.*

⁷⁶ *Id.* at 63.

for by hospital type and patient population.”⁷⁷ Once again, these outcomes support the information gathered from the published accounts, the interview, and the surveys.

C. Conclusions

The above data provides a glimpse into how HEC members approach consultations. There is indication that some members think it is important to consider how they are positioned in relation to the patient and family as well as how they are positioned within the health care system more broadly. The fact that some HEC members already attempt to consider their own partiality suggests that HECs and the individual members would be open to discussing the matter in a more organized and productive way and with the help of feminist scholarship. Furthermore, it is evident that HECs engage in some sort of principlist analysis, but it is not evident how this plays out and how it affects patients and other decisionmakers. Additionally, some HEC members tend to place more emphasis on the lives of individual patients than on how principles might apply to that individual (although it seems that the principles are not entirely abandoned). Notwithstanding the fact that DeRenzo and Strauss and other feminist scholars (whose work will be discussed in Chapter Two) maintain that principles can be utilized in combination with feminist approaches to HEC consultations, this thesis will show how the strong traditional bioethics and legal emphasis on principlism has hindered the implementation of a more feminist-centered approach to HEC consultations. Finally, because HECs operate in a complex system where moral questions are increasingly also becoming legal questions, it is imperative that HECs address the legal

⁷⁷ *Id.* at 63.

system's constraints on bioethical decisionmaking. Feminist bioethics and feminist legal theory can also help with this task. Chapter Two will examine the effects of principlism in HECs with the help of both feminist legal theory and feminist bioethics.

CHAPTER TWO: OBSTACLES TO SYSTEMATIC INTEGRATION OF FEMINIST THEORY IN HEC CONSULTATIONS

The relationship between courts and HECs is currently inadequate for producing the best outcomes for patients who are incompetent and whose families are faced with end-of-life decisions. There are two major cases that address the relationship between HECs and courts. The cases take two very different approaches to defining this relationship in the end-of-life context and each case has provided a model for other jurisdictions. The first major case, *In re Quinlan* (“*Quinlan*”), built HECs into the decisionmaking process.⁷⁸ The second major case, *Superintendent of Belchertown State School v. Saikewicz* (“*Saikewicz*”) rejected the reliance on HEC recommendations as intrusive upon the authority of the court.⁷⁹ Decades after *Quinlan* and *Saikewicz*, the relationship between HECs and the judiciary has not evolved with the increasing prevalence and influence of HECs in health care institutions and it has not evolved to meet the ethical demands created by new medical technologies. The haphazard nature of this relationship leads to concerns about upholding patients’ constitutional due process rights and providing quality patient care.

This chapter will begin by describing the *Quinlan* and *Saikewicz* cases in relation to their interactions with HECs. Then the academic response to these cases will be considered. *Quinlan* and *Saikewicz* generated intense debate within academic bioethics about the definition and role of HECs in end-of-life decisionmaking and this debate continues today. The concerns of and divisions between these scholars will be examined

⁷⁸ *In re Quinlan*, 70 N.J. 10 (1976).

⁷⁹ *Superintendent of Belchertown State School v. Saikewicz*, 373 Mass. 728 (1977).

to reveal that reliance on principlism both in the field of bioethics and in the law ignores the context of patients' lives. By blindly adhering to principlism and inadequately addressing context, bad outcomes for patients will result. It is important to address the interplay between bioethical and legal principlism in relation to HECs because principlism is so deeply embedded in both fields that it may implicitly and inadvertently shape HEC consultations, which are constrained by the law and informed by academic bioethics. Likewise, principlism is also likely to shape the relationship between HECs and courts. Reconceptualizing this relationship as one that relies less on principlism and more on context has great potential to not only serve patients but to also aid courts and other decisionmakers.

I. CURRENT CONCEPTIONS OF THE RELATIONSHIP BETWEEN HECS AND THE JUDICIARY

A. Judicial Definition of HECs' Role in End-of-Life Decisionmaking

The New Jersey Supreme Court, in *Quinlan*, was faced with determining whether Karen Quinlan's father, as her guardian, had the authority to discontinue life-sustaining treatment.⁸⁰ The court discussed the medical, ethical, and legal issues at length⁸¹ and finally concluded that Karen had a right to refuse the life-sustaining treatments under her Constitutional right to privacy.⁸² The court also found that since Karen could not exercise this right on her own behalf, her father, as her guardian, was able to exercise it for her.⁸³ Then the court discussed the difficulties that physicians might have in

⁸⁰ *Quinlan*, *supra* n. 78, at 18.

⁸¹ *Id.* at 23-41.

⁸² *Id.* at 41-42.

⁸³ *Id.* at 42.

terminating life-sustaining treatment, such as possible civil and criminal liability;⁸⁴ it instituted the involvement of HECs in order to relieve some of this burden. The court explains: “The most appealing factor [of HECs] seems to us to be the diffusion of professional responsibility for decision, comparable in a way to the multi-judge courts in finally resolving on appeal difficult questions of law.”⁸⁵ This statement indicates that when faced with a difficult end-of-life decision, a multitude of opinions will result in a better decision or at least will shield a physician who acts in good faith from bearing the burden of liability for a subjectively “wrong” decision in the eyes of the family.

The procedure the *Quinlan* court set forth is as follows: (1) the guardian and family of the patient must agree that ending treatment is the best course of action; (2) the attending physicians must agree that “there is no reasonable possibility of [the patient] ever emerging from her [or his] present comatose condition to a cognitive, sapient state and that life-support apparatus...being administered to [the patient] should be discontinued”;⁸⁶ (3) the physicians must consult with the HEC or a similar group in order to ensure that their assessment is correct; and (4) the life-sustaining treatment may be halted.⁸⁷ No one faces civil or criminal liability if this procedure is followed.⁸⁸ If there is disagreement among the parties outlined in this procedure, then judicial intervention is appropriate.⁸⁹ What is missing from the *Quinlan* decision is a standard by which a court might proceed in assessing a case before it. It is unclear whether a court should affirm

⁸⁴ *Id.* at 42-52.

⁸⁵ *Id.* at 49-50.

⁸⁶ *Id.* at 55.

⁸⁷ *Id.*

⁸⁸ *Id.*

⁸⁹ *Id.* at 50.

that the *Quinlan* procedure was followed, thus deferring to the decisionmakers involved in the procedure, or whether it should independently assess what the patient would have wanted.

In *Saikewicz*, the Massachusetts Supreme Court considered the case of a mentally disabled man who had cancer and required chemotherapy, which would not have cured the cancer but would have extended the length of his life by a few months to one year.⁹⁰ The court had to decide whether anyone was able to refuse “life-prolonging treatment,” whether the same legal standard would apply to patients who are competent and incompetent, and what the procedure should be for making such a decision.⁹¹ Unlike the *Quinlan* procedure, this court’s procedure does not include consultation with an HEC. Instead, it is purely judicial in that it first requires application to the court for a guardian or temporary guardian.⁹² The court may also appoint a guardian *ad litem* to ensure that the patients’ interests are represented.⁹³ Then the court must be persuaded that the person would have chosen to forego treatment.⁹⁴ If an HEC happens to become involved before the case is presented to the court, then the HEC may present its recommendations to the court just like any other witness. The court can do what it wants with the information provided by the HEC and the “additional advice or knowledge of any [other] person or group.”⁹⁵ Thus, the HEC is not a required part of the process. In fact, the court explicitly

⁹⁰ *Saikewicz*, *supra* n. 79, at 734-735 (Ultimately Mr. Saikewicz’s guardian and the court decided that treating the cancer would not be in his best interest).

⁹¹ *Id.* at 736.

⁹² *Id.* at 756.

⁹³ *Id.* at 757.

⁹⁴ *Id.*

⁹⁵ *Id.* at 757-758.

declines to follow the *Quinlan* court's inclusion of HECs in the decisionmaking procedure:

We take a dim view of any attempt to shift the ultimate decision-making responsibility away from the duly established courts of proper jurisdiction to any committee, panel or group, ad hoc or permanent. Thus, we reject the approach adopted by the New Jersey Supreme Court in the *Quinlan* case of entrusting the decision whether to continue artificial life support to the patient's guardian, family, attending doctors, and the hospital "ethics committee."⁹⁶

The court further expressed its disapproval of other groups, such as HECs, infringing on what it considers the sole domain of the judicial branch:

[S]uch questions of life and death seem to us to require the process of detached but passionate investigation and decision that forms the ideal on which the judicial branch of government was created. Achieving this ideal is our responsibility and that of the lower court, and is not to be entrusted to any other group purporting to represent the "morality and conscience of our society," no matter how highly motivated or impressively constituted.⁹⁷

As will be discussed at length in Section II, below, this language in *Saikewicz* is highly problematic. The court presumes that it is a neutral decisionmaker that can transcend what it considers to be a negative partiality, a partiality that, in the court's view, HECs cannot overcome. A few years later in *In re Spring*, the Massachusetts Supreme Court retracts some of its seeming disdain for the involvement of ethics committees when it indicates that such committees could be "highly persuasive on issues of good faith and good medical practice."⁹⁸ However, the court makes clear that it reserves ultimate

⁹⁶ *Id.* at 758.

⁹⁷ *Id.* at 759.

⁹⁸ *In re Spring*, 380 Mass. 629, 639 (1980).

decisionmaking for itself, especially in the event of “bad faith” on the part of physicians, HECs, and other “private” actors.⁹⁹

B. Concerns About HEC Decisionmaking Among Academic Bioethicists

The *Quinlan* and *Saikewicz* decisions spurred a healthy scholarly response to many issues, including the propriety of using HECs in the judicial end-of-life decisionmaking process. The *Quinlan* decision was the first time many people had been exposed to the idea of an ethics committee and it was therefore bound to raise some controversy. Beyond this initial debate, scholars have continued to both criticize and support the role of HECs in this process. The question of how much authority HECs should have when it comes to life and death decisions for patients who are incompetent remains unsettled.

The *Quinlan* and *Saikewicz* decisions also made it clear that there were divergent ways of thinking about the historically new problem of removing patients who are incompetent from life support. The definition of death was questioned and new ethical issues emerged.¹⁰⁰ Because of the gravity of the decision to terminate life-sustaining treatment for a patient who is incompetent, it became important to address who should make the decision and what sort of process should be implemented. It is informative to address the immediate scholarly response to *Quinlan* and *Saikewicz*, because these views set the stage for current thinking about how to best address end-of-life issues. They have also guided subsequent court decisions.

⁹⁹ Id.

¹⁰⁰ See e.g., Winston Chiong, *Brain Death without Definitions*, 35 *Hastings Ctr. Rpt.* 20 (2005).

The post-*Quinlan/Saikewicz* academic discussion primarily questioned whether the medical community or the courts should have more power over end-of-life decisionmaking for patients who are incompetent. Of course, the answers were diverse. The *Saikewicz* court thought the court should have more power because they were the only neutral body suited for the task.¹⁰¹ The medical community, however, was outraged by this claim. Relman thought that decisionmaking should go on as it always had, with physicians providing advice to patients and their families.¹⁰² If there was no dispute then there was no need to involve the courts. Buchanan agreed with Relman that the *Saikewicz* court overstepped its realm of expertise, but placed more emphasis on the family's role in deciding the best course of action for the patient.¹⁰³ Buchanan¹⁰⁴ and others¹⁰⁵ have accused Relman of medical paternalism, because of his views that physicians know the best course of treatment for patients because of their medical expertise. When HECs and other groups are added to the possibilities for ultimate decisionmaking authority, the debate becomes more complicated.

The definition of "hospital ethics committee" has also been the subject of intense debate. Annas¹⁰⁶ and Curran¹⁰⁷ argue that the *Quinlan* court meant "prognosis committee" when they included the ethics committee in the decisionmaking procedure.

¹⁰¹ *Saikewicz*, *supra* n. 79, at 758.

¹⁰² Arnold S. Relman, *The Saikewicz Decision: A Medical Viewpoint*, 4 Am. J. L. & Med. 233, 237-238 (1978).

¹⁰³ Allen Buchanan, *Medical Paternalism or Legal Imperialism: Not the Only Alternatives for Handling Saikewicz-type Cases*, 5 Am. J. L. & Med. 97, 99-100 (1979).

¹⁰⁴ *Id.* at 101.

¹⁰⁵ See e.g., Charles H. Baron, *Medical Paternalism and the Rule of Law: A Reply to Dr. Relman*, 4 Am. J. L. & Med. 337 (1978).

¹⁰⁶ George J. Annas, *Reconciling Quinlan and Saikewicz: Decision Making for the Terminally Ill Incompetent*, 4 Am. J. L. & Med. 367, 379 (1978).

¹⁰⁷ William J. Curran, *The Saikewicz Decision*, 298 N.E. J. Med. 499 (1978).

A prognosis committee is solely made up of physicians who purportedly have no bias toward the patient's prognosis and are therefore able to make an assessment of whether the attending physician's prognosis is medically proper. This would be different than the role of an HEC because HECs consider ethical questions rather than medical questions. Relman argued that a "peer review" mechanism would best serve the patient; it is unclear whether this is equivalent to a "prognosis committee."¹⁰⁸ Buchanan, on the other hand, seems to argue for an even more comprehensive and organized ethics committee than what was expected by the *Quinlan* court.¹⁰⁹ He would have the ethics committee serve two functions: (1) to create guidelines for physicians and families about how to approach the decisionmaking dilemma and (2) to oversee end-of-life decisionmaking in the hospital to ensure that no foul play occurs.¹¹⁰ If necessary, Buchanan's HEC would take a case to court if it felt there had been "procedural unfairness" or "substantive error."¹¹¹ Today, institutions use both HECs and prognosis committees in various capacities.

Scholars have also addressed the propriety of utilizing HECs in the end-of-life decisionmaking process. Some have rightly turned a critical eye toward certain aspects of HECs, including due process safeguards, defining the role of HECs in relation to the law, possible conflicts of interest, and the expertise of committee members. Others have minimized problems in these areas and focused on describing how we might make HECs more helpful to patients and others involved in end-of-life decisionmaking.

¹⁰⁸ Relman, *supra* n. 102, at 242.

¹⁰⁹ Buchanan, *supra* n. 103, at 111.

¹¹⁰ *Id.*

¹¹¹ *Id.* at 112.

One reason some scholars are concerned about giving too much power to HECs is that the HECs, unlike courts, are not required to ensure due process. Wolf points out that sometimes patients do not receive notice that the HEC is conducting a consultation.¹¹² This may happen because physicians request consultations more often than patients and medical charts are easily accessible.¹¹³ By contrast, a patient and his or her family will know if a court proceeding takes place because they are necessarily involved. Generally, all other interested parties are also involved. States have taken this concern into account when drafting legislation. For example, in Texas, the patient or the surrogate decisionmaker “shall be informed of the committee review process not less than 48 hours before the meeting called to discuss the patient’s directive.”¹¹⁴

Another concern is that HECs need not follow precedent in the decisionmaking process nor in the outcome. While the Joint Commission requires each hospital to have a way to deal with ethical issues, it does not require hospitals to follow any sort of protocol in reaching that goal.¹¹⁵ In the courts, patients can be fairly certain that their health problems will be dealt with in the same manner as patients in similar positions that came before them. There are also additional safeguards, such as the appeals process, that purport to ensure that a decision about the patient’s health will not be made arbitrarily. HECs, on the other hand, cannot promise the same uniformity because there is no procedural requirement that they treat like cases alike, beyond the task of determining

¹¹² Wolf, *supra* n. 2, at 812.

¹¹³ Robin Fretwell Wilson, Hospital Ethics Committees As the Forum of Last Resort: An Idea Whose Time Has Not Come, 76 N.C. L. Rev. 353, 388 (1998).

¹¹⁴ Tex. Health & Safety Code at § 166.046(b)(2).

¹¹⁵ The Joint Commission, *supra* n. 3, at RI.1.10.

what the patient would have wanted.¹¹⁶ Unlike court records, HEC decisions are private, making it difficult for patients to expect a certain type of outcome.¹¹⁷ Wilson suggests that, for these reasons, courts should not defer to the ethics committee recommendations.¹¹⁸ However, this thesis contends that ethical issues are so specific to individuals that uniformity and precedent are not as important in this context as they are in solving legal issues.

Another reason scholars are hesitant to divert decisionmaking power from courts to HECs is that the relationship between the two entities is ambiguous. Spielman argues that committee members are often called upon to give legal advice, or at least that the dividing line between legal and non-legal advice is blurry.¹¹⁹ Wolf suggests that it may be unclear to committee members and others whether the task of HECs is to consult or to make decisions.¹²⁰ She also argues that even if the decision is not the last step in the decisionmaking process, it may appear to a patient that the “decision” of the HEC is essentially final.¹²¹

Scholars also point to the possibility that conflicts of interest will arise between HECs and other parties involved in the decisionmaking process. The committees are designed to ensure quality patient care¹²² but are not always available for patient

¹¹⁶ Wilson, *supra* n. 113, at 393.

¹¹⁷ *Id.* at 397-398.

¹¹⁸ Wolf, *supra* n. 2, at 852.

¹¹⁹ Bethany Spielman, Has Faith in Health Care Ethics Consultants Gone Too Far? Risks of an Unregulated Practice and a Model Act to Contain Them, 85 Marq. L. Rev. 161, 194-197 (2001).

¹²⁰ Wolf, *supra* n. 2, at 808.

¹²¹ *Id.* at 809.

¹²² The Joint Commission, *supra* n. 3, at RI.1.10.

consultations.¹²³ It has been suggested, instead, that the committees are more apt to serve the needs of the institution or health care providers. Spielman argues that HECs have insitutional incentives to prevent litigation.¹²⁴ For instance, HEC members as well as the institution that created the committee may view the role of the HEC as one that protects the institution from liability.¹²⁵ She says, “[w]hen health providers violate patients’ or families’ rights, some ethics consultants will ‘keep the case’ even if that means not following up on a patients rights violation....”¹²⁶ This means that when an HEC member has the power and responsibility to identify a situation that does not best serve the needs of the patient, the committee member may feel pressured to keep the situation quiet. Adding to this pressure is the fact that many HEC members are hired and paid by the institution.¹²⁷ At least, Wilson argues, the HEC members’ relationship with the institution will compromise objectivity in consultations.¹²⁸ This concern assumes that objectivity is possible and desirable, which this thesis challenges.

These scholars are also concerned that the relationship between HEC members and health care providers creates another conflict of interest. Again, Wilson points to the possibility that the relationship will undermine HEC objectivity.¹²⁹ Wolf suggests that the problem may be procedural: the committee is probably run by physicians and there

¹²³ Wolf, *supra* n. 2, at n. 10 (citing Stuart J. Youngner et al., *A National Survey of Hospital Ethics Committees*, 11 *Critical Care Med.* 902, 904 tbl. 4 (1983) (The Youngner study was published in 1983. It found that 63 percent of HECs allowed families to request consultations and only 25 percent of patients were allowed to do so.) (Wolf’s concern about notice may be less important today; see McGee et al., *supra* n. 1, at 62 tbl. 4).

¹²⁴ Spielman, *supra* n. 119, at 190-191.

¹²⁵ *Id.* at 190.

¹²⁶ *Id.* at 191.

¹²⁷ *Id.* at 190.

¹²⁸ Wilson, *supra* n. 113, at 389.

¹²⁹ *Id.*

are few requirements that the patient be provided information about what the physician has presented to the committee in a dispute.¹³⁰ Additionally, there is the concern that some committees function more as a means for physicians to immunize themselves from liability both formally through legislation and informally due to a diffusion of responsibility for the decision.¹³¹ This concern is not unfounded. Arizona, for example, has a statute that immunizes physicians from liability if they make a “good faith medical decision” after consulting with an ethics committee.¹³² Even without formal immunity, Spielman argues that conflicts of interest may arise due to the relationship between the health care providers and the HEC.¹³³ She explains that committee members may rely on physicians for good employment evaluations, connections to professional opportunities, and simply to maintain an amicable working environment.¹³⁴

Finally, scholarly and judicial attention has focused on the fact that HEC members need not have any special ethics training and some have accordingly argued that courts should not defer to HEC recommendations. Wilson argues that because HEC members need not have any special training over judges, and because they rely on “experts” just as judges do, judges should make the decisions.¹³⁵ Additionally, she points out that many decisions do not require any special training because they are more normative than ethical.¹³⁶ Both Wilson¹³⁷ and Spielman¹³⁸ imply that committee

¹³⁰ Wolf, *supra* n. 2, at 812-813.

¹³¹ Spielman, *supra* n. 119, at 178-179.

¹³² Ariz. Rev. Stat. Ann. at § 36-3231(C).

¹³³ Spielman, *supra* n. 119, at 184.

¹³⁴ *Id.* at 184-185.

¹³⁵ Wilson, *supra* n. 113, at 385-386.

¹³⁶ *Id.* at 375.

¹³⁷ *Id.* at 385-386.

members are constrained from objectivity by their own beliefs, especially because they have had no ethics training and are not subject to due process constraints. Wolf warns that it is easy for courts to defer to HECs for medical decisionmaking because physicians have traditionally carried out this task, but that “courts may fall into the trap of seeing ethics committees as the best arbiters of what constitutes an appropriate treatment decision.”¹³⁹ Perhaps Wolf is too hasty in concluding that HECs are not the best arbiters. Similarly, it is unclear that the courts would better fulfill this particular decisionmaking role.

Feminist legal and bioethical scholarship (including some of Wolf’s contributions) has exposed the ways in which the judiciary and dominant academic bioethics have used principalist analytical frameworks to obscure how social and institutional forces shape peoples’ health care experiences. Because HECs are shaped by the legal profession and the field of bioethics, it is likely that they will adopt some of the analytical approaches developed by courts and bioethicists. Therefore, HECs are likely to perpetuate the minimization of the effects that social and institutional forces have on patients’ lives. Principalism looks slightly different in the legal context than it does in the bioethical context, but its main premise is that “we” can devise or deduce principles from what we know about the law or what we know about varying expressions of morality that will help us solve any dilemma that is presented. The problem is that the “we” is usually one or more white, upper-class men who decide what the principles will be, to which problems the principles will apply, and how the principles will apply to a particular set of

¹³⁸ Spielman, *supra* n. 119, at 187-189.

¹³⁹ Wolf, *supra* n. 2, at n. 46.

facts.¹⁴⁰ The sections that follow will explain how principlism is utilized as a dominant mode of analysis in the judiciary and in the field of bioethics. Feminist works will illuminate the weaknesses of adhering to principlism as it is currently conceptualized.

II. RETHINKING THE RELATIONSHIP BETWEEN HECS AND THE JUDICIARY: CHALLENGING THE PRIMACY OF PRINCIPALISM

A. Judicial Principlism and Feminist Criticisms

Judicial principlism is the idea that principles guide court decisions and that the law exists independently of the beliefs and opinions of judges and independent of the facts of a particular case.¹⁴¹ One of the foundational texts espousing this theory is *Toward Neutral Principles of Constitutional Law* by Herbert Wechsler.¹⁴² Wechsler explains that adhering to principles derived from the Constitution ensures that judges are not able to exercise indiscriminate power on a case-by-case basis.¹⁴³ In other words, according to neutral principlists, this approach is the one that is most likely to uphold the Constitution, including equality and fair administration of justice.¹⁴⁴

Wechsler argues that in most cases it is easy to find the underlying principles. In the face of anticipated opposition Wechsler confronts cases that threaten his theory. For example, Wechsler was troubled by the decision in *Brown v. Board of Education*, which

¹⁴⁰ Until recently, the law explicitly privileged masculine lawmaking through the “reasonable man” standard. After feminists identified this standard as sexist it was changed to the standard of a “reasonable person.” Change the name was one step toward making law more responsive to people who are not white or male or wealthy but the law must continue to evolve in order to reach that goal. See e.g., Caroline A. Forrell & Donna M. Matthews, *A Law of Her Own: The Reasonable Woman as a Measure of Man* (NYU Press 2001).

¹⁴¹ Ronald D. Rotunda & John E. Nowak, *Neutral Principles or Process-Oriented Jurisprudence*, 5 *Treatise on Const. L.* § 23.5, § 23.5(a) (3rd ed. 2007).

¹⁴² Herbert Wechsler, *Toward Neutral Principles of Constitutional Law*, 73 *Harvard L. Rev.* 1 (1959).

¹⁴³ *Id.* at 12.

¹⁴⁴ Rotunda & Nowak, *supra* n. 141, at § 23.5(d).

did not seem to overtly rely on any previously stated principle. Many people saw this school desegregation case as the beginning of constitutional equal protection based on race.¹⁴⁵ Considering that this protection did not previously exist, it seems that the court probably created a new principle. In order to rationalize his theory, he identified a possible underlying principle: that segregation “[denies] equality to the minority against whom it is directed” and that perhaps the liberty that is at issue is the freedom of association.¹⁴⁶ However, it seems that he is ultimately unable to fit the case into his theory of principalism.¹⁴⁷

Even though Wechsler’s article was written in 1959, it has followers today. For example, Massachusetts Supreme Court Justice Ireland explained that a previous case had set forth the principle that the state cannot use gender as a category in regulating marriage.¹⁴⁸ He wrote an extensive explanation about why this principle should apply to the case at hand and based his view on Wechsler’s article.¹⁴⁹ Justice Ireland was very explicit in his adherence to Wechsler’s conception of neutral principalism and he seems to be unique in his focused application of the theory. Many cases merely cite Wechsler’s article as the authority on principalism with no discussion of its content.¹⁵⁰ This indicates

¹⁴⁵ Wechsler, *supra* n. 142, at 31 (discussing *Brown v. Board of Education*, 347 U.S. 483 (1954)).

¹⁴⁶ *Id.* at 33-34.

¹⁴⁷ *Id.*

¹⁴⁸ *Cote-Whiteacre v. Department of Public Health*, 446 Mass. 350, 397 (2006) (dissenting opinion by Justice Ireland).

¹⁴⁹ *Id.* at 395-396.

¹⁵⁰ See e.g., *Pigford v. Veneman*, 355 F.Supp.2d 148, 169 (D.D.C. 2005); *Hoblock v. Albany County Bd. Of Elections*, 487 F.Supp. 2d 90, 96 (N.D.N.Y. 2006); *F.D.I.C. v. Hamilton*, 122 F.3d 854, 866 (10th Cir. 1997) (in dissent).

that Wechsler's ideas have been so widely adopted that explanation of his arguments is no longer necessary.

Not all judges are as explicit or as methodical about their adherence to neutral principles as Justice Ireland, but it seems that the theory underlies much of current jurisprudence. John Hart Ely argues that several theories about the judiciary's function attempt to avoid the problem that judges use their own values in decisionmaking. One of the theories Ely discusses is Wechsler's neutral principalism; some other theories that uphold neutrality are natural law (judges find the law) and reason (philosophical logic guides judges in decisionmaking). As Ely explains, the dominant idea, despite variations in application, is that the judiciary's role is to articulate fundamental principles.¹⁵¹ As Ely points out, these ideas about judicial "neutrality" and "reason" are widely supported and valued in the legal community, and therefore challenging the value of those approaches meets much opposition. As discussed above, legal scholars are concerned about HECs' ability to uphold constitutional due process rights. HECs are likely to respond to those concerns by mimicking principalist judicial approaches to protecting due process rights.

Feminist legal theory, however, has boldly disputed the validity of neutral principalism. Catharine MacKinnon describes Wechsler's neutral principalism as "distill[ing] principles by sanitizing value judgments to the point where no one's name is

¹⁵¹ John Hart Ely, *Foreword: On Discovering Fundamental Values*, 92 Harv. L. Rev. 5, 16 n. 55 (1978).

discernible on them.”¹⁵² In other words, neutral principalism efficiently conceals white, male, upper-class privilege (and other privileges). Alternatives to principalist approaches might better safeguard all people’s due process rights. Underlying her argument are concerns about how peoples’ lives are affected by court decisions that are masked by a false neutrality. A guise of neutrality makes systemic judicial partiality difficult to challenge while explicit partiality would be easier to challenge.

Feminist legal theory has made clear that judicial neutrality is a myth. Martha Minow describes how people are systemically disadvantaged when judicial neutrality is the goal.¹⁵³ Her analysis begins with her “dilemma of difference” theory, where she argues that attaining equality for all individuals is thwarted by the fact that in some cases equality will be upheld if we recognize differences and in some cases it will be upheld if we do not recognize differences.¹⁵⁴ For instance, affirmative action programs treat different groups of people differently in order to secure equality by mandating that, for example, people of color are accorded preference over white people for employment positions or educational opportunities. Alternatively, *Brown v. Board of Education* illuminates one way that different groups of people are to be treated the same: by desegregating schools and therefore theoretically providing the same educational opportunities to both black and white students.¹⁵⁵ The cornerstone of Minow’s “dilemma of difference” is that by recognizing difference in the law we stigmatize individuals who

¹⁵² Catharine A. MacKinnon, *Women’s Lives, Men’s Laws* 66 (Belknap Press of Harvard U. Press 2005).

¹⁵³ Martha Minow, *Making All the Difference: Inclusion, Exclusion & American Law* (Cornell U. Press 1990).

¹⁵⁴ *Id.* at 20-21.

¹⁵⁵ *Brown*, *supra* n. 145.

embody the categories that have been created.¹⁵⁶ To that same end, if we fail to recognize differences we risk allowing discrimination to continue because we have no space to talk about it.¹⁵⁷

Minow describes five “unstated assumptions” that perpetuate “dilemmas of difference.”¹⁵⁸ The first of these assumptions is: “Difference Is Intrinsic, Not a Comparison.”¹⁵⁹ Minow explains that the law relies on categories as a means of analysis but that sometimes the categories turn into something that people believe is reality.¹⁶⁰ For example, the Americans with Disabilities Act (“ADA”) prohibits discrimination based on disability in a number of contexts including employment, education, and in public accommodations.¹⁶¹ But the ADA does not precisely define who is disabled. Instead, the legislative branch creates guidelines and the judiciary decides which individuals on the margins of the guidelines will be protected by the ADA.¹⁶² In other words, categories are not intrinsic to people, the law creates them.¹⁶³ Often this is forgotten.

¹⁵⁶ Minow, *supra* n. 153, at 20-21.

¹⁵⁷ *Id.*

¹⁵⁸ *Id.* at 50.

¹⁵⁹ *Id.* at 53.

¹⁶⁰ *Id.* at 53-54.

¹⁶¹ Americans with Disabilities Act of 1990, 42 U.S.C. §§ 12101-12117 (2006).

¹⁶² See e.g., *Martinson v. Kinney Shoe Corp.*, 104 F.3d 683 (4th Cir. 1997) (finding that a shoe salesperson with epilepsy is not protected by the ADA because store security is an essential function of the job that cannot be overcome by a reasonable accommodation); *Lenzinger v. County of Lake*, No. 323870 (N.D. Cal. Feb. 5, 2008) (finding that employee with an injured wrist is not protected by the ADA because she could not carry out the essential functions of the job of juvenile corrections officer with or without a reasonable accommodation).

¹⁶³ Minow, *supra* n. 153, at 53-55.

The second unstated assumption delineated by Minow is: “The Norm Need Not Be Stated.”¹⁶⁴ When someone challenges the status quo, he or she will be compared to the underlying group of people who benefit from keeping the status quo. The individual who is different than the individuals who embody the norm will be scrutinized, but the norm will not need to be stated. Minow gives the example of women attempting to gain equal opportunities in the workplace.¹⁶⁵ One of the excuses for not granting women equal opportunities was that they could become pregnant and that would have detrimental effects on the workplace, the woman, and the home. What was unstated was that women would be expected to fit into the workplace that was designed for men who had women supporting them outside of the workplace.¹⁶⁶ So not only would men lose jobs to women, they would also lose the women who made it possible for them to keep up the work hours to which they were accustomed. Rather than analyzing the problem in terms of the institutions in place, the courts analyzed the “problem” of women in the workplace.¹⁶⁷

The third unstated assumption is: “The Observer Can See without a Perspective.”¹⁶⁸ The legal profession has decided that it is best if judges approach the cases before them from a neutral standpoint. Minow suggests that this is impossible and that what happens under the guise of neutrality is that the dominant viewpoint (or the norm from the second assumption) is furthered. She gives several case law examples, including the case of *Plessy v. Ferguson*, where the Supreme Court Justices were unable

¹⁶⁴ *Id.* at 56.

¹⁶⁵ *Id.*

¹⁶⁶ *Id.*

¹⁶⁷ *Id.*

¹⁶⁸ *Id.* at 60.

to imagine themselves in the position of “the colored race” who were forced to ride in separate train cars than whites.¹⁶⁹ The result of this case was the “separate but equal” rationale that persisted for many years.

The fourth assumption is that “Other Perspectives Are Irrelevant.”¹⁷⁰ Sometimes people rely so heavily on stereotypes that they will fail to see the possibility of other perspectives.¹⁷¹ This builds on the previous assumption because not only are norms unstated, alternatives are not even imagined.¹⁷² For instance, in *McCleskey v. Kemp*, the Court dismissed the possibility that judicial biases resulted in harsher sentencing of convicted murderers who are black than convicted murderers who are white, especially if a black man kills a white person.¹⁷³ Despite statistical proof, the Court distinguished the individual case from the statistics.¹⁷⁴

The final unstated assumption is that “The Status Quo is Natural, Uncoerced, and Good.”¹⁷⁵ Following from this assumption is the problem that it is very difficult to challenge the status quo because it is constructed so that discussion of it is unnecessary for its maintenance. Minow describes three underlying propositions that support this assumption:

First, the goal of governmental neutrality demands the status quo because existing societal arrangements are assumed to be neutral. Second, governmental actions that change the status quo have a different status from omissions, or failures to act, that maintain the status quo. Third,

¹⁶⁹ *Id.* at 64-65 (citing *Plessy v. Ferguson*, 163 U.S. 537 (1896)).

¹⁷⁰ *Id.* at 66.

¹⁷¹ *Id.*

¹⁷² *Id.*

¹⁷³ *Id.* at 67.

¹⁷⁴ *Id.*

¹⁷⁵ *Id.* at 70.

prevailing societal arrangements are not forced on anyone. Individuals are free to make choices and to assume responsibility for those choices. These propositions are rarely stated, both because they are deeply entrenched and because they treat the status quo as good, natural, and freely chosen – and thus not in need of discussion.¹⁷⁶

By failing to recognize that the status quo is constructed, that it is not always good, and that it is not freely chosen by everyone, the dilemma of difference is perpetuated because people will be forced to fit into an unchallenged status quo and will be stigmatized as “different” if they fail to conform. Depending on the category of difference, the effects can be devastating to real people who embody the category. The five unstated assumptions outlined by Minow make it possible for power to stay in the hands of a few. Although Minow’s dilemma of difference targets the legal system, it is equally applicable to HECs that utilize principalist approaches.

MacKinnon argues that when judges hide behind neutrality, powerful parties are able to manipulate the “neutrality” in a way that cannot be challenged by less powerful parties.¹⁷⁷ This is one way that neutral principalism upholds the privileges it disguises. To challenge false neutrality is to challenge the legal profession – an entity that is not likely to change without a fight. MacKinnon suggests that we need not do away with principles but that principles should be based on the effect they will have in real peoples lives and they should be open to scrutiny.¹⁷⁸ While emphasizing her faithfulness to democracy, MacKinnon adds that judges should not be able to state their oppressive

¹⁷⁶ *Id.*

¹⁷⁷ MacKinnon, *supra* n. 152, at 5.

¹⁷⁸ *Id.* at 6.

opinions without recourse simply because they have been explicit.¹⁷⁹ Instead, the process of creating judicial principles should be open to contestation – the core value of a democracy.¹⁸⁰

In order to illuminate the fact that principles are based on substance and not on some source outside of the particular facts of a case, MacKinnon points to the principle of the constitutional right to privacy.¹⁸¹ She explains that “[p]rivacy’ becomes the second-order derivative abstract vehicle for... substance.”¹⁸² The privacy right came about after the Court heard various cases about sexuality and reproduction, including cases about abortion, contraception, and sexual acts.¹⁸³ Although this shows the ways in which the law relies on substance, many conservative legal scholars have contested the existence of the privacy right and think that the Court erred in finding one.¹⁸⁴

The scholarly legal community has generally resisted or been unable to challenge the substance behind the neutrality of the judiciary. Kathleen E. Mahoney explains that critiques of judicial decisions have often focused on their logic rather than their substance.¹⁸⁵ Even when legal scholars address policy and social implications of decisions, judges are rarely criticized for using stereotypes or other flawed analytical

¹⁷⁹ *Id.* at 9.

¹⁸⁰ *Id.*

¹⁸¹ *Id.* at 7.

¹⁸² *Id.*

¹⁸³ *Id.*

¹⁸⁴ See e.g., *Roe v. Wade*, 410 U.S. 179 (1973) (White, J., dissenting); David Helscher, *Griswold v. Connecticut and the Unenumerated Right of Privacy*, 15 N. Ill. L. Rev. 33 (1994); Ernest E. Katin, *Griswold v. Connecticut: The Justices and Connecticut’s “Uncommon Silly Law,”* 42 Notre Dame L. Rev. 680 (1967); Frank R. Goldstein, *The Constitutional Right of Privacy: “A Sizeable Hunk of Liberty,”* 26 Md. L. Rev. 249 (1966).

¹⁸⁵ Kathleen E. Mahoney, *The Myth of Judicial Neutrality: The Role of Judicial Education in the Fair Administration of Justice*, 32 Willamette L. Rev. 785, 792-793 (1996).

tools and the resulting discriminatory decisions.¹⁸⁶ This is problematic if one considers how Minow's unstated assumptions work to camouflage the substance. It is not only the judiciary that operates under the assumptions, but most of the rest of the legal community as well.

The privilege underlying neutral principalism is also supported by the fact that the judiciary's task is to decide cases based on individual claims rather than on identity-based experiences, or systemic problems.¹⁸⁷ This makes it very difficult to have a meaningful legal discussion about how group-based identities affect decisions. Or, as Minow would claim, it makes it very hard to discover how difference is constructed and serves to reinforce and uphold the status quo.¹⁸⁸ Mahoney explains that there is concern that as the judiciary becomes more diverse that these judges will rely on their experiences to decide cases.¹⁸⁹ This fear relates directly back to Minow's unstated assumptions, namely that "the observer can see without a perspective."¹⁹⁰ Mahoney elaborates that "[t]he accepted wisdom is that, collectively, judges are impartial and that occasionally, an individual judge may 'slip up.' When this happens, an individual judge can be overturned on appeal, reprimanded, or in extreme cases, impeached."¹⁹¹ Judges already rely on experiences to decide cases and when this fact is ignored, social factors and the influence they have on individuals' problems continue to be ignored by the judiciary as a whole. The same problem arises when HECs make recommendations without exposing their

¹⁸⁶ *Id.*

¹⁸⁷ *Id.* at 792.

¹⁸⁸ Minow, *supra* n. 153, at 50.

¹⁸⁹ Mahoney, *supra* n. 185, at 792.

¹⁹⁰ Minow, *supra* n. 153, at 60.

¹⁹¹ Mahoney, *supra* n. 185, at 792.

processes and partialities. If patients and families are unable to question the substance of HEC recommendations, their health care experience may be less than ideal.

Even though principlism quietly upholds privilege as it is currently conceptualized, it may not be necessary to do away with principlism as long as principles are constituted in a different way. MacKinnon, as mentioned briefly above, would like to see principles that are derived from people's lives. She discusses the merits of bottom-up versus top-down reasoning and concludes that the U.S. Constitution has allowed second-class citizens to exist in the U.S.¹⁹² Her solution to this is to start from the bottom (people's lives) and work her way up (to the Constitution) so that the Constitution has a chance to fulfill its promise of equal protection.¹⁹³ Because the law has traditionally taken the top-down approach, it is evident that the top-down approach is not going to ensure equal protection.¹⁹⁴

Mahoney also sees a way to make principles attentive to social context. She suggests that judges need to be educated on the ways in which "variables such as gender, poverty, race, illiteracy, disability, discrimination, alcohol and drug abuse, and sexual and physical abuse have an impact on both social behaviour and the judges' own decisions."¹⁹⁵ Some organizations have begun to employ this type of legal education campaign.¹⁹⁶ Mahoney might agree with MacKinnon when she says:

¹⁹² MacKinnon, *supra* n. 152, at 66-67.

¹⁹³ *Id.*

¹⁹⁴ *Id.*

¹⁹⁵ Mahoney, *supra* n. 185, at 819.

¹⁹⁶ *See e.g.*, the International Project to Promote Fairness in the Administration of Justice and Legal Momentum.

If it is instrumentalism or consequentialism, as opposed to principled, to care about the outcome of this process, then call what I do something other than principled. Alternatively, show me someone who is indifferent to the human consequences of their principles and I will show you someone who is in great need of what the word integrity implies.¹⁹⁷

In sum, judicial principlism has been at odds with attention to the facts of the case and the substance of people's lives. What these feminist legal scholars point out is that all principles are attentive to someone's substance but that this substance relies on unstated hierarchies of power so that those in charge of the legal system see the results they want from the principles that have been enumerated. Those people whose identities differ from the status quo will learn that their lives are often not vindicated by legal principles. Feminist legal theory has much to offer in the way of changing the legal system and it also has much to offer HECs because of the interconnections between the use of principlism in the law and in bioethics.

B. Bioethical Principlism and Feminist Criticisms

Bioethicists have devised many methods for interrogating bioethical dilemmas. One of the most popular methods of analysis is principlism, which takes its most well-known form as the principles outlined in Principles of Biomedical Ethics by Tom L. Beauchamp and James F. Childress.¹⁹⁸ These principles, which serve as “a framework for identifying and reflecting on moral problems,” have been widely read by scholars and used in the clinical context.¹⁹⁹ In fact, the principles have even been influential in countries such as Brazil, where the theory is used to the exclusion of all other bioethical

¹⁹⁷ MacKinnon, *supra* n. 152, at 71.

¹⁹⁸ Tom L. Beauchamp & James F. Childress, *Principles of Biomedical Ethics* (5th ed. Oxford U. Press 2001).

¹⁹⁹ *Id.* at 15.

theories.²⁰⁰ The work of Beauchamp and Childress has been especially revered because it is the first text to set forth a general framework for bioethics rather than merely dealing with specific issues.²⁰¹ In recognizing that the field is diverse, this thesis uses the work of Beauchamp and Childress as an example of how principlism (even if its form changes) has failed to attend to the social context people's lives.

The core of Beauchamp and Childress's theory relies on the four principles of respect for autonomy, non-maleficence, beneficence, and justice, which the authors chose to help reflect on the moral dilemmas that occur in health care settings.²⁰² The goal of these four principles is to uphold at least the "common morality." The common morality is a baseline morality on which all moral people can agree (e.g., do not kill, do not lie, do not steal, etc.).²⁰³ These principles reach beyond the field of bioethics so that people who are not ethicists can easily understand their significance. For instance, the U.S. Constitution would seem to protect autonomy under the guise of liberty and the Hippocratic oath commands that doctors must try to help their patients (beneficence) and must not harm them (non-maleficence). The next few paragraphs briefly describe how Beauchamp and Childress conceptualize these principles and the role they play in helping to analyze bioethical issues. It is important to keep in mind that the four principles are used as an analytical framework and are not in and of themselves answers to solving the problems encountered in health care.

²⁰⁰ Debora Diniz & Ana Cristina Gonzalez Velez, *Feminist Bioethics: The Emergence of the Oppressed in Globalizing Feminist Bioethics* 62 (Rosemarie Tong, Gwen Anderson & Aida Santos eds., Westview Press 2001).

²⁰¹ Robert M. Veatch, *When Ethical Paths Converge*, 9 *Hastings Ctr. Rpt.* 48 (1979).

²⁰² Beauchamp & Childress, *supra* n. 198, at 12.

²⁰³ *Id.* at 3.

The principle of respect for autonomy, as understood by Beauchamp and Childress, “is, at a minimum, to acknowledge that person’s right to hold views, to make choices, and to take actions based on personal values and beliefs.”²⁰⁴ Their conception of autonomy consists of three conditions. First, an autonomous action is intentional. A doctor or hospital may require that a patient give written and signed informed consent to a procedure in order to increase the likelihood that the consent was intentional. Second, an autonomous action is carried out with understanding. In order to ensure that the patient understands the procedure to which he/she gives consent, it is necessary for someone to explain the procedure in terms that the patient can understand. It may also be necessary to determine whether the patient has enough competence to consent at all. A young child, for instance, will not have enough competence to give informed consent and a guardian will need to make decisions for the child. Finally, an autonomous action is carried out without controlling influences.²⁰⁵ In the case of giving consent, a patient may be pressured by family members or medical staff, for example, to choose a particular course of action. If the patient signs the consent forms because of this pressure, then respect for the patient’s autonomy is not honored.

The principle of non-maleficence commands that health care professionals do no harm to their patients.²⁰⁶ Beauchamp and Childress explain that this differs from “doing good” because non-maleficence is merely a requirement that a person must refrain doing something that might cause harm, rather than an affirmative requirement to make a

²⁰⁴ *Id.* at 63.

²⁰⁵ *Id.* at 59.

²⁰⁶ *Id.*

situation better.²⁰⁷ This does not mean that a person must only refrain from doing something intentionally bad (e.g., murder another person), but that it is necessary to refrain from doing something that might put someone at risk of harm.²⁰⁸ In the health care context, this might mean that failing to check a patient's vital signs at the appropriate time would violate the principle. Sometimes in health care it is unclear what the principle would require a decisionmaker to do. For instance, it may be intentionally harmful to leave a person on life support or it may be intentionally harmful to remove the person from life support.²⁰⁹

The principle of beneficence is related to non-maleficence. Rather than implicating an obligation to refrain from harming another person, beneficence is an affirmative requirement to help another person, to prevent them from being harmed, or to stop harm that is already occurring.²¹⁰ Beauchamp and Childress divide the principle into two obligations. One is the obligation of "positive beneficence," which "requires agents to provide benefits."²¹¹ The other is "utility," or the requirement that "agents balance benefits and drawbacks to produce the best overall results."²¹² Some actions taken by health care providers seem to clearly uphold the principle of beneficence: setting a broken bone or providing oxygen to a patient who is having trouble breathing. Other actions may not be as clearly beneficent: discontinuing life support for a person in a vegetative state who has no hope of recovery.

²⁰⁷ *Id.*

²⁰⁸ *Id.* at 117.

²⁰⁹ *Id.* at 144.

²¹⁰ *Id.* at 115.

²¹¹ *Id.* at 165.

²¹² *Id.*

The final principle, justice, seems to be the most elusive to the authors. They describe several theories (including utilitarian, libertarian, communitarian, and egalitarian theories) that each have contemporary supporters but they find it undesirable to restrict the principle of justice to any one conception. The problems that the principle helps solve are easier to identify. For instance, many people in the U.S. do not have enough money to pay for health care and therefore, the “just” thing to do might be to implement a universal health care system.²¹³ The principle of justice would also grapple with an unequal distribution of health care across lines of gender or race, for example.²¹⁴ Another area where the principle of justice is considered is in the distribution of a limited supply of artificial organs.²¹⁵ Fairly deciding who receives these organs is difficult, especially considering that some people cannot pay for them and that health is already distributed unevenly along socioeconomic lines.

At first glance, the principles delineated by Beauchamp and Childress seem adequate for identifying and analyzing ethical dilemmas that arise in health care. However, feminist bioethicists who contribute to the construction of a feminist “ethics of power” argue that principlism ignores, to its detriment, the interpersonal and systemic power relations inherent in institutionalized health care.²¹⁶ Principlism ignores these

²¹³ *Id.* at 239.

²¹⁴ *Id.* at 237-238.

²¹⁵ *Id.* at 253.

²¹⁶ There are two broad categories of feminist bioethics: the ethics of care and the ethics of power. The ethics of care is attributed to the early work of Carol Gilligan, whose research exposed gender biases in tests to determine children’s developmental stages of moral reasoning. Gilligan found that girls were more likely to value collaboration and cooperation than boys. Gilligan argued that the two ways of moral thinking should indicate equal moral development. Carol Gilligan, *In a Different Voice: Psychological Theory and Women’s Development* (Harvard U. Press 1982). Feminist bioethicists who work to expose an ethics of power think that the

important components by claiming to begin from a neutral vantage point; it ignores power by relegating feminist contributions to the status of a “partial ethics”; and finally, it ignores power by failing to recognize that difference exists. By recognizing that principles and those who apply them are not neutral, patients who are not privy to health care’s power systems will be better served.

Bioethics reinscribes the power dynamics that already exist within health care. Wolf argues that “[w]e have developed a bioethics primarily for the person with access to health care and with a doctor likely to listen to, understand, and respect that person. It is a bioethics for the privileged.”²¹⁷ In fact, western medicine was designed as a paternalistic profession, taking power away from women in knowledge domains, such as midwifery, that had been informally passed on for centuries.²¹⁸ In recent U.S. medical history, the implications of paternalism have sometimes been shocking. For instance, in the 1970s hundreds of thousands of young, mostly poor and mostly black women were sterilized against their will or without their knowledge of the ramifications of the procedures performed on them.²¹⁹ Often paternalism comes disguised as “beneficence,” one of Beauchamp and Childress’s central principles. Although Beauchamp and

failure to challenge or investigate the source of the gendered differences essentializes women and fails to account for social context. Diniz and Velez suggest that the ethics of care may even reinforce power relations. Diniz & Velez, *supra* n. 200, at 63. The feminist works utilized in this thesis contribute to the ethics of power branch of feminist bioethics.

²¹⁷ Susan M. Wolf, *Introduction: Gender & Feminism in Bioethics in Feminism & Bioethics: Beyond Reproduction* 18 (Susan M. Wolf ed., Oxford U. Press 1996).

²¹⁸ Barbara Ehrenreich & Deidre English, *For Her Own Good: Two Centuries of the Experts’ Advice to Women* 103-108 (Anchor Books, 2nd ed., 2005).

²¹⁹ Dorothy Roberts, *Reconstructing the Patient: Starting with Women of Color in Feminism & Bioethics: Beyond Reproduction* 124 (Susan M. Wolf ed., Oxford U. Press 1996).

Childress agree that paternalism is improper and that beneficence is not a euphemism for paternalism, the fact is that remnants of the not-so-distant paternalistic past remain.

Even the principle of respect for autonomy is conceptualized by traditional bioethicists in a way that reinscribes existing power relations in the health care system. A focus on autonomy as the primary guiding principle for bioethical decisionmaking first assumes that people operate as individuals that are removed from the communities in which they live.²²⁰ This focus also ignores how lack of power constrains people's exercise of choice.²²¹ Choosing between two bad options is not a purely autonomous act if a more privileged person would have better choices.²²² Susan Sherwin explains how the focus on autonomy overlooks important considerations in health care decisionmaking:

In asserting the theoretical primacy of the individual, autonomy-based theories characterize social and moral obligations as essentially secondary to considerations of self-interest. They treat communities and the ties that bind them as a problem that must be accounted for, while proceeding as if the concept of an individual apart from community were coherent. And they ignore the fact that our sense of ourselves and our preferences is very much a product of our social history and current circumstances.²²³

Other analytical frameworks for bioethical decisionmaking are possible and feminist bioethicists like DeRenzo and Strauss have attempted to implement alternative frameworks in the clinical setting.

Dorothy E. Roberts offers an alternative analytical starting point for bioethics. She argues that poor women of color have a unique perspective on oppressive practices

²²⁰ Susan Sherwin, *Feminism & Bioethics in Feminism & Bioethics: Beyond Reproduction* 52-53 (Susan M. Wolf ed., Oxford U. Press 1996).

²²¹ *Id.*

²²² *Id.* at 58.

²²³ *Id.* at 53.

of physicians and on the institution of medicine.²²⁴ This perspective serves as the best starting point for creating a feminist bioethics that challenges power relations in health care:

[b]ecause racism makes the oppressive use of medicine so obvious to many of them, women of color may be more suspicious of doctors' claims of beneficence. Denied the privileges of race and class, these women have the least to gain from the present institution of medicine and the most to gain from changing it.²²⁵

Physician authority plays a part in the conversations with patients that are already shaped by gender, race, and class dynamics.²²⁶ Roberts provides an example of how this works. It is ten times more likely that a pregnant black woman will be reported for drug addiction than it is that a pregnant white woman will be reported.²²⁷ This indicates that health care professionals, in conjunction with the criminal justice system, have decided to exercise control over women's choices.²²⁸ The result of this control is that poor black women's access to health care (in this case for prenatal care) decreases further because they fear legal sanctions.²²⁹

Even seemingly equal relationships within medicine, as between two HEC members who are white and economically privileged for instance, are subject to gendered power dynamics. Rubin and Zoloth-Dorfman go so far as to claim that gender affects the balance of power in relationships more than any other factor (including race, class, and

²²⁴ Roberts, *supra* n. 219.

²²⁵ *Id.* at 117.

²²⁶ *Id.* at 124.

²²⁷ *Id.* at 128.

²²⁸ *Id.*

²²⁹ *Id.* at 129.

age).²³⁰ They explain that HEC members (like all people) are “marked” by their gender and that marking affects how clinical ethics discourse is constructed. Those who are marked by the dominant gender will have more moral agency in health care decisionmaking than those marked by a non-dominant gender.²³¹ One way this plays out is through physician-nurse relationships. Not only are these roles gendered, but the respective professions are also constructed hierarchically, which frequently tips the balance of power even farther toward the male health care decisionmaker.

Again, one of the reasons that these imbalances of power persist is that bioethical problems are analyzed from an alleged “neutral” viewpoint. Neutrality, however, is not possible nor is it desirable for bioethical analysis. Even though deduction of a “common morality” seems laudable, Wolf argues that the “the relevant community and rules of agreement are rarely stated.”²³² As with legal principlism, it is possible that the problem lies not with the principles themselves, but in the way those principles are created and applied. Nelson explains that what often happens in practice is that issues such as race, gender, and class might be used by decisionmakers to determine which principles are implicated and the extent of each principle’s importance in the particular situation. However, after the principles are determined and ranked, the decisionmaker is then free to “judge impartially.”²³³ Tong argues that if principles are the starting point for

²³⁰ Susan Rubin & Laurie Zoloth-Dorfman, *She Said/He Said: Ethics Consultation and the Gendered Discourse*, 7 J. Clinical Ethics 321, 321 (1996).

²³¹ *Id.* at 326 (Even though Rubin & Zoloth-Dorfman and other sources engaged in this thesis discuss gender only in terms of men and women, this thesis does not assume that gender is binary.).

²³² Wolf, *supra* n. 217, at 25.

²³³ Nelson, *supra* n. 8, at 500.

bioethical analysis, it will be necessary to make endless exceptions to what were identified as “commonalities” because commonalities were never really discovered in the first place.²³⁴ Thus, the biases of those analyzing an ethical dilemma remained unexamined and it is likely that social context is not considered. Indeed, this parallels Roberts’s argument that we should listen to what poor women of color have to say about health care because their lives are usually seen as exceptions.²³⁵

The claim by traditional bioethicists that “[a] feminist [bio]ethics will always be a partial ethics,” also serves to diminish the importance of the social forces that shape bioethical decisionmaking.²³⁶ The statement implies that Beauchamp and Childress’s work, which, as mentioned above has been heralded for being the first text to set forth a general framework for bioethics, is a complete ethics. In other words, a feminist bioethics is only applicable to women and a traditional bioethics is applicable to everyone. Indeed, that was the goal of Beauchamp and Childress. However, the statement misses the point of feminist work: a feminist bioethics is also meant to be a complete ethics. Mary Rawlinson explains that feminist bioethics aims to produce a bioethics that attests to “universal” principles with as much legitimacy as traditional bioethics, which is conceptualized not from the bodies and lives of humans, but from the bodies and lives of men.²³⁷ In principlism, the implied subject, “man,” is expected to

²³⁴ Rosemarie Tong, *Is a Global Bioethics Possible As Well As Desirable?: A Millennial Feminist Response in Globalizing Feminist Bioethics* 33 (Rosemarie Tong, Gwen Anderson & Aida Santos eds., Westview Press 2001).

²³⁵ Roberts, *supra* n. 219.

²³⁶ Mary C. Rawlinson, *The Concept of a Feminist Bioethics*, 26 *J. Med. & Philosophy* 405, 405 (2001).

²³⁷ *Id.* at 412.

apply to all people. Rawlinson asks traditional bioethicists to consider their moral dilemmas from the standpoint of women's lives in order to see if their principles are truly applicable to everyone.²³⁸ Traditional bioethicists might soon find that what distinguishes principlism from a feminist bioethics of power is that principlism ignores difference and a feminist bioethics of power starts from difference – not that feminists are only concerned about women.

Difference should be a starting point for bioethics rather than something to ignore. By denying that differences exist, social forces are once again ignored and many people will be disserved by bioethics. Difference is conceptualized broadly here and can mean difference along lines of gender, race, or class, for example, or difference in conceptualizing morality cross-culturally. Feminist bioethics has been compared to cultural relativism, a bioethics that argues that there is no common morality because morality differs from culture to culture.²³⁹ While feminists acknowledge this concept broadly, they argue that just because morality differs from culture to culture does not mean that the cultures are acting morally.²⁴⁰ Instead, Diniz and Velez argue that: “...feminist moral relativism does not accept as moral the practices of all communities, but only those communities that treat all of its members with equal respect and consideration.”²⁴¹ The one value that is absolute under feminist moral relativism is that oppression is a moral wrong.²⁴² Therefore, starting with difference does not mean that

²³⁸ Id.

²³⁹ Diniz & Velez, *supra* n. 200, at 64-65.

²⁴⁰ Id.

²⁴¹ *Id.* at 65.

²⁴² Id.

feminists will overlook harmful “moralities.” Rather, different moralities are acknowledged and analyzed overtly, rather than through the essentialist lens of principlism. It is naïve to think that all people will adhere to one conceptualization of morality or that moral dilemmas can be assessed using the same framework. However, recognition of divergent moralities comes with the task of assessing each for its contribution to harmful stereotypes and societal practices.

As mentioned in Chapter One, DeRenzo and Strauss suggest that even if principles can be applied neutrally, the next step of ranking the principles may cause conflict.²⁴³ Thus, traditional model of ranking principles and values tends to disregard the viewpoints of people who would rank the principles and values differently.²⁴⁴ Interrogating how social forces affect moral decisionmaking means that we must consider a person’s membership or perceived membership in a group.²⁴⁵ For example, women make up a group that is, in general, treated differently than men within health care. Not only does a person’s affiliation with a group affect how that person experiences health care, but it also affects health care professionals’ attitudes toward that person. The same may be said for how a bioethicist interprets a moral dilemma or how an HEC member approaches a consultation. While people can feign a neutral viewpoint, they cannot shed the social forces that inform their analytical process.

Wolf says that traditional bioethics has ignored important discourses, including feminist scholarship, critical theory, critical race theory, and postmodern scholarship

²⁴³ DeRenzo & Strauss, *supra* n. 6, at 215.

²⁴⁴ *Id.*

²⁴⁵ Wolf, *supra* n. 217, at 17.

when other disciplines, including the law, have paid attention.²⁴⁶ It is time for these discourses to play a part in constructing clinical ethics practice. Because there is no best decisionmaker for difficult bioethical dilemmas and because HECs have the flexibility to adapt and innovate much more readily than either the medical community or the judiciary,²⁴⁷ HECs should be the entity to experiment with new modes of bioethical decisionmaking. In making this argument, this thesis recognizes that HECs are imperfect as well. At times HECs must contend with sharp opposition to their practices and even to their existence. Therefore, Chapter Three suggests how HECs may gain clout within the health care system and the judiciary in a way that allows them to retain flexibility in their practices. Ideally, this combination of clout and flexibility will allow for alternative discourses to contribute to bioethical decisionmaking and thereby benefit patients.

²⁴⁶ *Id.* at 20.

²⁴⁷ Both are complex systems that have deeply entrenched practices, constrained by professional oversight and resistance as well as by law.

CHAPTER THREE: OVERCOMING OBSTACLES TO THE IMPLEMENTATION OF FEMINIST HEC CONSULTATIONS

I. A LEGAL SOLUTION FOR FACILITATING FEMINIST HEC CONSULTATIONS

Before feminist approaches to bioethical decisionmaking will impact patients' lives through HEC consultations, HECs must have some power to influence bioethical decisionmaking in the health care system and in the judiciary. As outlined in Chapter Two, not all courts value the contributions of HECs in end-of-life decisionmaking and many scholars are skeptical about the haphazard organization and implementation of HECs.²⁴⁸ In order to assuage some of these fears and doubts, this chapter devises a plan that works within a familiar legal framework. This plan aims to help make the relationship between HECs and courts more productive as well as to help HECs shape their practices in a way that increases their legitimacy in bioethical decisionmaking. The following plan is designed with patients in mind because it allows for patients to be recognized as individuals in a complex system where they are often only recognized as statistics, injuries, and diseases. The plan likewise aims to decrease the reliance on bioethical and legal principalism in end-of-life decisionmaking.

HECs have become an integral part of bioethical decisionmaking in hospitals. Because bioethical decisions often have legal ramifications, it is time to define HECs' role in the judicial process. The following framework, which defines the relationship between HECs and courts, will utilize the standard for judicial deference to agency decisions set forth in *Skidmore v. Swift* ("Skidmore").²⁴⁹ This chapter does not argue that

²⁴⁸ See e.g., Wilson, *supra* n. 113; Wolf, *supra* n. 2; Spielman, *supra* n. 119.

²⁴⁹ *Skidmore v. Swift*, 323 U.S. 134 (1944).

HECs should become agencies. Instead it argues that HECs and agencies have similar characteristics and that agency deference jurisprudence can provide insights into how courts and HECs can coexist in a way that best serves patients.

To begin, this chapter describes agency deference jurisprudence, focusing on the contributions of *Skidmore*. The first section provides the necessary background for the second section, which relies on *Skidmore*'s rationale to describe the how HEC experience, flexibility, and expertise positively contribute to the end-of-life decisionmaking process in ways that courts cannot. Finally, *Skidmore*'s framework is applied to show how judicial deference to HEC recommendations can serve patients, courts and HECs.

A. Agency Deference Jurisprudence

Judicial deference to agencies came about in the Progressive Era and really began to take hold with the New Deal.²⁵⁰ During this time it was perceived that experts were needed to turn the economy around and that those experts were located in government agencies.²⁵¹ The courts accordingly deferred to agency actions because "...the regulatory agency itself was seen as the embodiment of the public interest."²⁵² In the 1960s, as a result of the civil rights movement, the courts and Congress responded to political activism that called for more citizen participation in politics.²⁵³ This shift reflected the

²⁵⁰ Robert B. Horwitz, *Judicial Review of Regulatory Decisions: The Changing Criteria*, 109 *Political Sci. Q.* 133, 137 (1994).

²⁵¹ *Id.*

²⁵² *Id.* at 140.

²⁵³ *Id.* at 135

lack of confidence that agencies would actually make decisions in the public interest.²⁵⁴ Since that time a “compromise standard of review” has developed.²⁵⁵ Horwitz explains that this standard reflects the values of both agency expertise and public participation.²⁵⁶ The balance of expertise and accountability can manifest itself in HECs through judicial deference to HEC recommendations.

Skidmore was decided in the midst of the judicial trend to defer to agency expertise, but it sets forth a flexible standard that also promotes agency accountability.²⁵⁷ The *Skidmore* Court ruled that even though agency decisions do not bind courts, they provide a “body of experience and informed judgment to which courts and litigants may properly resort for guidance.”²⁵⁸ In applying *Skidmore*, the standard for determining how much guidance the agency will provide is based on “all those factors which give it power to persuade.”²⁵⁹ The court delineates some of those factors: “thoroughness evident in [the agency’s] consideration, the validity of its reasoning, [and] its consistency with earlier and later pronouncements.”²⁶⁰ The Court further explains that deference is given to agency decisions because the decisions are “based upon more specialized experience and broader investigations and information than is likely to come to a judge in a particular case.”²⁶¹ Between 1944 and 1984, *Skidmore* guided courts in deferring to agency rulings.

²⁵⁴ *Id.*

²⁵⁵ *Id.*

²⁵⁶ *Id.*

²⁵⁷ *Skidmore*, *supra* n. 249, at 134.

²⁵⁸ *Id.* at 140.

²⁵⁹ *Id.*

²⁶⁰ *Id.*

²⁶¹ *Id.* at 139.

In 1984, the U.S. Supreme Court, in *Chevron v. Natural Resources Defense Council* (“*Chevron*”), returned to an increased focus on agency expertise but described a new rationale for judicial deference to agency decisions: congressional delegation of power.²⁶² For seventeen years after *Chevron*, the legal community was under the impression that *Skidmore* deference had been replaced.²⁶³ Then the Court decided *Christensen v. Harris County*²⁶⁴ (2000) and *U.S. v. Mead*²⁶⁵ (2001) and *Skidmore* deference was revived. Although Justice Scalia has charged that *Skidmore* is “anachronistic” and has strongly voiced his disagreement with its revival,²⁶⁶ the Court

²⁶² In 1984 the Court decided *Chevron*, which increased the deference afforded to agencies in its two-part test. The first part of the test, which may end the inquiry immediately, asks: has Congress “directly spoken to the precise question at issue”? If the answer is yes, the statute trumps any other interpretation. If the answer is no, then the court proceeds to the second part of the test, which asks: has the agency made a “permissible construction of the statute”? In order to determine what constitutes a permissible construction, the court must determine if Congress explicitly or implicitly gave the agency the power to make binding laws, thereby filling in gaps in the statute. If Congress gave the agency explicit power, then the court may only reject the agency’s interpretation of the statute if it is “arbitrary, capricious, or manifestly contrary to the statute.” If Congress implicitly empowers the agency, then the court need only determine if the agency’s interpretation is “reasonable.” The court based its *Chevron* rationale for deference on the implied delegation of powers and only secondarily rationalized it on the basis of agency expertise and experience. *Chevron v. Nat. Resources Def. Council*, 467 U.S. 837 (1984).

²⁶³ Scalia argues that “...the majority’s approach compounds the confusion it creates by breathing new life into the anachronism of *Skidmore*, which sets forth a sliding scale of deference....” *U.S. v. Mead*, 533 U.S. 218, 250 (2001) (Scalia, J., dissenting).

²⁶⁴ In *Christensen*, the Court made clear that *Chevron* did not overrule *Skidmore* and that the two standards of agency deference work together. In *Christensen*, the interpretation at issue was contained in an opinion letter from the Department of Labor. The Court said: “Interpretations such as those in opinion letters – like interpretations contained in policy statements, agency manuals, and enforcement guidelines, all of which lack the force of law – do not warrant *Chevron*-style deference.” *Christensen v. Harris Cty.*, 529 U.S. 576, 587 (2000).

²⁶⁵ *Mead* reiterated *Christensen*’s holding with regard to *Skidmore*. *Mead*, *supra* n. 263, at 218.

²⁶⁶ *Id.* at 250.

remained firm that, even for informal rulings, agencies have “specialized experience” that deserves some deference.²⁶⁷

Krotoszyński argues that *Chevron*’s focus on the implied-delegation rationale was a digression from the “roots of deference.”²⁶⁸ He explains that the Court’s rulings between *Skidmore* and *Chevron* provide support for the expertise and experience rationale and argues that *Mead* and *Chevron* wrongly neglect it by creating the delegation-of-power rationale. In *S.E.C v. Chenery Corp.* (“*Chenery*”), for example, Justice Murphy explains that an agency deserves the “greatest amount of weight” when its decision is “the product of administrative experience, appreciation of the complexities of the problem, realization of statutory policies, and responsible treatment of uncontested facts.”²⁶⁹ In other words, if an agency applies its experience and follows procedures, it deserves deference. Likewise, *F.T.C. v. Cement Institute* (“*Cement Institute*”) indicates that “...prior experience with a problem enhances the agency’s ability to respond to the problem effectively.”²⁷⁰ *Chenery* and *Cement Institute*, like *Skidmore*, were decided before the civil rights shift to a participatory model of agency deference, but they indicate that the original focus on agency expertise was influential for several decades and has resurfaced again.²⁷¹ The focus on agency expertise as a rationale for judicial deference provides insight into how the relationship between HECs and the courts might best serve

²⁶⁷ *Id.* at 235.

²⁶⁸ Ronald J. Krotoszyński, *Why Deference?: Implied Delegations, Agency Expertise, and the Misplaced Legacy of Skidmore*, 54 *Admin. L. Rev.* 735, 755 (2002).

²⁶⁹ *Id.* at 740 (citing *S.E.C. v. Chenery Corp.*, 332 U.S. 194, 209 (1947) (citations omitted)).

²⁷⁰ *Id.* at 741 (citing *F.T.C. v. Cement Institute*, 333 U.S. 683 (1948)).

²⁷¹ Horwitz, *supra* n. 250.

patients. Before applying the *Skidmore* framework to HEC-court interactions, it is first necessary to explain the extent of HEC experience, flexibility, and expertise, thereby establishing the propriety of extending judicial deference to HEC recommendations.

B. HEC Experience, Flexibility, and Expertise

Skidmore rationalized judicial deference to agency decisions based on agencies' experience, flexibility, and expertise in their respective fields. Like agencies, HECs possess experience, flexibility, and expertise that courts do not possess when it comes to end-of-life decisionmaking. First, HECs have experience thinking about and dealing with tough bioethical issues brought on by technological, medical and social evolutions. HECs will ideally value, above all else, the well-being of patients who come to face bioethical dilemmas in a complex health care system. Courts, on the other hand, do not specialize in sorting through the complexities of the health care system. HEC experience comes from working in the hospital setting, working with grieving families, and working with physicians and other health care professionals. Next, HEC flexibility is evident in the ability to attend to the particular needs of the community the hospital serves and in the ability to quickly adapt to previously non-existent medical complexities and the changing bioethical norms presented by these developments. Finally, these experiences and flexibilities add up to a collective expertise that will better serve patients in the end-of-life decisionmaking process.

The setting within which HECs encounter the bioethical problems raised by end-of-life circumstances is important because it gives HECs a situated view of the case. Moral and technical questions must be decided in the setting of a health care institution

that has a complicated set of social relations, mixing emotions with complex medical knowledge and health care bureaucracy. Because HECs are located within this setting, they are able to navigate these complex relations from vantage points that are not available to the courts. Courts, unlike HECs, must set particular boundaries on the amount of time they spend hearing the different parties. They must hear the parties in a space that is formal, unfamiliar, and removed from the site of the decision. Judges cannot go to patients' bedsides to observe which parties visit most often. Nor can they observe how particular physicians interact with patients. Additionally, from their locations within hospitals, HECs can observe the workings of the institution and any pressures from the administration that might constrain a physician's or a patient's decision. Although many value the so-called objectivity and "detached but passionate"²⁷² disposition of the courts, the tragic circumstance of deciding whether to remove someone from life-support is a circumstance that cannot be separated from the complex medical setting. HECs have both the ability to be "detached but passionate"²⁷³ and the opportunity to observe the physical space and social interactions that create the complexity.

HECs also spend their time working with grieving families who must make important medical decisions for loved ones. Part of this task includes listening, asking questions, providing support, and trying to help the parties resolve a conflict before it escalates and the judicial system becomes involved. Courts, on the other hand, are merely equipped to resolve disputes without the benefit of specialization in dealing with grief. The courts may often deal with grieving and aggrieved parties, but this is different

²⁷² *Saikewicz, supra* n. 79, at 759.

²⁷³ *Id.*

than attending to the particular mindset of someone who faces the death of a loved one. The court is restricted to hearing a formalized rendition of the family's feelings.

Additionally, HECs are accustomed to working with physicians and other health care professionals who also have particular needs in the end-of-life decisionmaking process. While Spielman argues that HECs' relationships with health care workers might cause conflicts of interest and ultimately disserve the patient and patient's family,²⁷⁴ this thesis maintains that the HEC-physician relationship provides insight into conflicts that might arise between the physician and the family. Moreover, knowing the fears of health care providers will better prepare HECs to clarify the ethical problems and conflicts that arise. In other words, HECs can serve as a sort of translator between the very different worlds of health care professionals and patients because they have experience working with both groups and ideally have members of both groups serving on the committee.

The role of the HEC as intermediary is related to the concern that HECs serve to unjustly immunize health care providers from liability.²⁷⁵ The involvement of the HEC probably indicates²⁷⁶ that there is no clear ethical decision, that the interested parties are conflicted about which course of action to choose, and that the physician is ill equipped or ill advised to deal with the situation alone. In these cases any protection of the physician is secondary to the goal of patient and family well being. Properly functioning HECs minimize the need for medical malpractice suits not because they seek to protect physicians, but because they involve the family in the decision-making process, validate

²⁷⁴ Spielman, *supra* n. 119, at 184.

²⁷⁵ *Id.* at 178-179.

²⁷⁶ George Khushf & Rosemarie Tong, Setting Organizational Ethics Within a Broader Social and Legal Context, 14 HEC Forum 77, 82 (2002).

their concerns, and solve communication problems between physicians and families. Additionally, Wolf points out that if HECs protect patients' rights through due process, the "...delay, formality, and expense of judicial proceeding" will be unnecessary in most cases.²⁷⁷ The same might also be said for malpractice proceedings. Indeed, the best result would be for the HEC to minimize conflict and aid in reaching a decision that will prevent family members from pursuing litigation, not because the family members feel they are unable to bring suit but because they feel validated in the decisionmaking process.

The relationship between HECs and health care institutions might also prove helpful for clarifying ethical issues involved in end-of-life decisionmaking. Some fear that HECs' position within the institution might cause conflicts of interest.²⁷⁸ For instance, it is possible that the HEC might take on a risk management function, thereby privileging the needs of the institution over the needs of patients. However, knowledge of the institution's goals can be filtered through the thoughtfulness of HEC consultation. Health care institutions have a lot of power and work hard to meet institutional goals. Sometimes those goals serve patients collectively in ways that are not evident to individual patients. For example, cutting costs in one area may mean the institution will be able to continue providing services in another area (e.g., emergency services). If HECs are privy to institutional priorities and operational strategies, they can consider how patients will be affected. This has the potential to benefit the patients and other decisionmakers because the institutional strategies will affect patient care whether or not

²⁷⁷ Wolf, *supra* n. 2, at 853.

²⁷⁸ Spielman, *supra* n. 119, at 190-191; Wilson, *supra* n. 113, at 389.

they are made explicit. Patient and family interests will still trump institutional and health care professionals' interests in HEC consultations and patients and families will be better served because the HEC will be able to help them navigate the health care bureaucracy.

In addition to valuable experience, an HEC can be flexible in attending to the characteristics of the particular community the hospital serves and it can quickly adapt to changing bioethical norms presented by new medical complexities. Each hospital has unique characteristics that vary depending on factors such as geographical location and community demographics. Some hospitals serve primarily middle-class insured patients, but others serve low-income uninsured patients. Hospital demographics also vary along lines of race, ethnicity, and other factors that change the dynamics of health care interactions. HECs have the flexibility and expertise to adapt to needs of the community because they are located within the community. Ideally, HECs include members from the communities they serve, making them even more attentive to specific concerns.²⁷⁹ Courts, on the other hand, are not granted the flexibility to adapt to these varying needs and concerns. The law purports to treat all people the same, but this fails to account for the reality that all people are not the same.²⁸⁰ For example, studies show that "...people of color are more likely than whites to distrust health care providers and the U.S. health

²⁷⁹ Mitchell M. Handelsman, *Canaries in the Mine Shaft: Frustrations and Benefits of Community Members on Ethics Committees*, 7 HEC Forum 278 (1995).

²⁸⁰ *E.g.* Wilson, *supra* n. 113, at 381-382 (Arguing that *stare decisis* is an important principle that HECs do not uphold.).

system.”²⁸¹ This distrust, which is based on historical social inequalities, might also lead patients of color to “question the motives underlying...physician decisionmakers at the end of life.”²⁸² The quality of end-of-life care for all patients will be improved if community dynamics are considered and objectivity is downplayed.

HECs are also flexible in their ability to adjust to previously non-existent medical complexities and the changing bioethical norms presented by these developments. Once again, courts are less able to exercise creativity in dealing with diverse circumstances. Fletcher suggests that HECs should have a national voice in discussions about morality in health care decisionmaking.²⁸³ HECs have experience working closely with and facilitating communication between patients, families, health care providers, and administrators. This experience provides insight into bioethical issues that courts do not have the opportunity to access. Even though the courts will ultimately make determinations that may have the effect of guiding conceptualizations of bioethics, it should be HECs and others who work in the health care setting that primarily guide the courts and not the other way around.

Finally, HECs have collective expertise in end-of-life decisionmaking, which makes judicial deference to their recommendations appropriate. Each member of an HEC contributes a different sort of expertise. For example, physicians and nurses contribute their medical knowledge, social workers contribute their expertise in identifying

²⁸¹ B. Jennings et al., *Access to Hospice Care. Expanding Boundaries, Overcoming Barriers*, Mar-Apr. Hastings Ctr. Rpt. S3, S39 (2003).

²⁸² Id.

²⁸³ John C. Fletcher, *The Bioethics Movement and Hospital Ethics Committees*, 50 Md. L. Rev. 859, 872 (1991).

problems and advocating solutions that best serve the patient, lawyers bring the ability to identify relevant legal issues, religious leaders are skilled in dealing with grief, and administrators bring great knowledge about the particular institution's ability to deal with complex medical problems. In fact, courts recognize each of these people as experts and allow them to testify to their knowledge in court. The expertise of an HEC does not come from these individual experts, however, but instead manifests as a collective expertise when all of these perspectives are combined. Even community members who do not work within the health care setting contribute to the collective expertise. Handelsman explains that a good community member will challenge the reasoning of the other members by pointing out different perspectives.²⁸⁴ The community member might also be able to explain the nonmedical viewpoint of the patient to the doctor (who might change her approach or opinion as a result), thereby serving as an excellent patient advocate.²⁸⁵

HECs' expertise also comes from the benefits of working as a group. Instead of denying that HECs have expertise because many members lack formal ethics training, it is better to think of HEC expertise as a collective knowledge about how to access the diverse values, concerns, and fears present in each end-of-life situation. Groupthink theory suggests that when groups, and individuals within groups, are held accountable for their decisions and when there are procedures in place for them to follow, they can

²⁸⁴ Handelsman, *supra* n. 279, at 280.

²⁸⁵ *Id.* at 280-281.

operate remarkably well.²⁸⁶ This thesis presents a framework for judicial deference to HEC recommendations, set forth below, which combines the two elements of group work and procedure.

It is important to stress that HECs should not be designed to replace the family in end-of-life decisionmaking for a patient who is incompetent. Instead, HECs should serve to help the family work through a tragic circumstance. Even though the family takes precedent in the decision, Justice Dore, dissenting in *In re Colyer*, explains that there are times when families “might be motivated by less than worthy considerations.”²⁸⁷ These motives might include collecting from the patient’s estate after her death, preserving funds that might otherwise pay for extended care, or wanting to preserve bodily life because of religious beliefs that differ from the patient’s. The HEC would identify improper motives and prevent them from guiding the decisionmaking process by highlighting alternatives that keep the best interests of the patient at the forefront. Although the courts are also skilled at identifying improper motives, HECs could identify them before they turn into improper actions and legal issues. The next section describes how judicial deference to HECs will encourage the development of due process safeguards. The following framework will vindicate the rights of patients and provide guidance for building a relationship between HECs and courts in end-of-life decisionmaking.

²⁸⁶ Marceline B. R. Kroon, David van Krevald & Jacob M. Rabbie, *Group Versus Individual Decision Making: Effects of Accountability and Gender on Groupthink*, 23 *Small Group Research* 427, 453 (1992).

²⁸⁷ *In re Colyer*, 99 Wash.2d 114, 145 (1983).

C. Applying *Skidmore* Rationale to HEC-Court Interactions

HECs are here to stay unless bioethical dilemmas disappear from hospitals or hospitals find another way to deal with these dilemmas. HECs serve an important function in end-of-life decisionmaking both because of the unique contributions they bring to the process and because of their widespread use resulting from Joint Commission accreditation requirements for hospitals.²⁸⁸ It is important to establish a relationship between HECs and courts because it is very likely, if not inevitable, that their paths will cross. This final section will begin by describing a typical situation that might lead to HEC-court interaction. Then it will provide an alternative solution, based on the standard set forth in *Skidmore*, to the currently haphazard or non-existent framework for judicial review of HEC recommendations.

A typical case²⁸⁹ that might lead to interaction between HECs and the courts begins with a patient who is incompetent and whose life is sustained by machines. It is unclear whether this patient should continue to receive treatment. Due to the severity and/or complexity of the situation, someone (e.g., the attending physician or the family) requests a consultation with the HEC. The HEC then spends time meeting with all interested parties, including the patient's family, friends, nurses, and physicians. After some deliberation and collaboration, the committee issues its recommendation to either continue or withdraw treatment from the patient. In this hypothetical case, the family

²⁸⁸ The Joint Commission, *supra* n. 3, at RI.1.10.

²⁸⁹ It is important to note that all HECs operate differently so that not all HECs will conduct clinical consultations in this way. However, based on research and discussions with former HEC members, this "typical case" is generally representative of some HEC consultations.

disagrees with the recommendation of the HEC and seeks a different result by petitioning the court.

In end-of-life cases, the current state of the law allows each judge to decide who may testify at the proceeding and how much weight to give each witness's testimony. It is possible that the court will hear testimony from the HEC. Under the standard proposed in this thesis, the court would hear all interested parties but pay particular attention to the persuasiveness of the HEC's recommendation. This is where *Skidmore* applies.²⁹⁰ *Skidmore* delineates three factors that will determine the persuasiveness of an agency decision, but also leaves room for the court to consider other relevant factors. Here it is argued that courts should use *Skidmore*'s three factors to consider HEC recommendations as well as any other relevant factors. First, the court should assess how thorough the HEC was in its investigation and recommendation.²⁹¹ The court might ask if the HEC interviewed all interested parties and what kinds of questions it asked. This point is important because it will require HECs to accord interested parties the opportunity to be heard. It will also require that the questions are thorough enough to elicit important information about patients that is necessary to final HEC recommendations.

Second, the court should assess the "validity of [the HEC's] reasoning."²⁹² This element is important for judicial review of HEC recommendations because it will encourage HECs to think about and promulgate guidelines for reviewing cases. It might also encourage them to write down their decisionmaking process, thereby providing

²⁹⁰ *Skidmore*, supra n. 249.

²⁹¹ *Id.* at 140.

²⁹² *Id.*

patients an explanation as to the reasoning behind the decision. Additionally, this element of review could encourage HECs to take responsibility for making decisions that were based on someone's interests besides the patients' (e.g., the institution or the physician) or to avoid doing this in the first place.

Third, the court should look to the HEC's "consistency with earlier... pronouncements."²⁹³ For HECs this element of review should be restricted to procedural consistency rather than substantive consistency because HECs need to retain their ability to adapt to the needs of individuals. Procedural consistency might mean that an HEC has a list of questions or a checklist that guides them through each step of the consultation. For instance, the consultation model developed by DeRenzo and Strauss (see Appendix A) would serve as a guide for HECs. If an HEC followed this model for each consultation, it would have procedural consistency. Substantive consistency, on the other hand, would mean that if there were two similar end-of-life cases the resulting recommendation of the committee would need to be the same for each case. This is where requiring consistency is unnecessary and may not uphold patients' rights. For instance, the decision to remove a ventilator from one patient who is incompetent need not determine that the ventilator should be removed from all patients who are incompetent. Flexibility in the substantive areas of HEC decisionmaking should be

²⁹³ Id.

retained. Under the consistency inquiry the court may decide to review the case *de novo* if the HEC does not follow procedural guidelines.²⁹⁴

Finally, courts should assess other factors that seem important to the HEC's analysis of the particular case because *Skidmore* provides that the foregoing factors along with "all those factors which give it the power to persuade" will determine the weight of the decision.²⁹⁵ If the judge finds that the HEC's decision lacks the "power to persuade" then it is free to decide the case *de novo*. In order to fulfill the ultimate goal of creating an efficient and sensitive system for resolving end-of-life dilemmas, the courts should also provide guidance on the ways in which HECs can improve their decisionmaking process so that future patients can avoid the burden of going to court.

This framework may seem to suggest that the recommendations of HECs are privileged over the opinions of patients or family members. However, the ideal HEC will vindicate the rights of patients and the feelings of family members better than the courts. The goal of extending *Skidmore*-type deference is to enable HECs to reach this ideal level of functioning. If an HEC does not accomplish this goal, the court can step in and provide a remedy for the patient as well as a reason for the HEC to alter its practices. Krotoszyński provides the basis for this interplay with his proposal for judicial deference to all types of agency decisions.²⁹⁶ Under his standard, an agency must prove that it used

²⁹⁴ *De novo* means that a court reviews the facts of the case and makes a new decision rather than reviewing the procedure used to come to the first decision and deciding whether that procedure was proper.

²⁹⁵ *Skidmore*, *supra* n. 249, at 140.

²⁹⁶ Krotoszyński's standard would do away with *Chevron* deference to formal agency decisions and would create one standard against which all agency decisions could be assessed. Krotoszyński, *supra* n. 268.

its expertise in making a particular decision.²⁹⁷ By extrapolating from *Skidmore*, he explains that an agency has two choices: (1) it can use procedure to secure deference or (2) it can forego the use of procedure and risk that a court will give no deference and overrule its decision.²⁹⁸ He argues that this standard upholds *Skidmore*'s rationale, which indicates that "[a]n agency decision should receive a level of judicial deference that is more or less proportionate to the degree of confidence that the reviewing court has in the procedure associated with the agency reaching its decision."²⁹⁹ As long as HECs make decisions based on the procedures they set forth; as long as HECs are thorough, apply valid reasoning, and are consistent; and as long as reviewing courts have confidence in the HEC procedures, then HEC recommendations should similarly receive judicial deference.³⁰⁰

II. CONCLUSION

Granting *Skidmore*-type deference to HEC recommendations will create benefits for patients, courts, and HECs. It will encourage all HECs to adopt mechanisms to ensure procedural fairness and uphold patients' rights. Upholding patients' rights obviously benefits patients, but it also benefits HECs and courts. It requires HECs to assess whether they are meeting the needs of patients. Likewise, self-assessment is an essential function of the committee if it is to truly uphold patients' due process rights.³⁰¹ Courts will benefit because they are more equipped to review due process standards than

²⁹⁷ *Id.* at 752.

²⁹⁸ *Id.* at 753.

²⁹⁹ *Id.* at 754.

³⁰⁰ *Id.* See also Kroon et al., *supra* n. 286, at 427.

³⁰¹ Wolf, *supra* n. 2, at 851.

bioethical dilemmas. In fact, Relman explains that in *Saikewicz*,³⁰² the court usurped the decisionmaking power that had traditionally been exercised by patients, families, and physicians when it made the rule that all end-of-life decisions must come before the court.³⁰³

Deference will also encourage continuity of process while still allowing for a diversity of approaches and outcomes. This is where feminist theory plays a role. One of the most valuable aspects of the above plan is that it allows for HECs to individualize their approaches to bioethical decisionmaking. This means that new approaches can be tested in a way that will not disturb legal procedure as it now stands (although perhaps it should be disturbed). Instead, feminist approaches to the decisionmaking process can enrich the experience for patients who will be treated as individuals with widely varying conceptions of morality. HEC members may already have a heightened understanding of how culture, race, class and other factors relevant to the community might affect end-of-life decisions in a particular hospital. As was discovered in the research conducted for this thesis, some HEC members are inclined to think about such factors. With a little help from feminist bioethics and feminist legal theory, HECs can further raise their awareness of how social context affects their patients' decisionmaking and how that decisionmaking can be helped by some legal values (e.g., due process) and how it can be hindered by other legal values (e.g., blind adherence to hegemonic principalism).

Judicial deference to HEC recommendations will define the relationship between courts and HECs while valuing their respective roles. HECs will still be able to adapt to

³⁰² Saikewicz, *supra* n. 79.

³⁰³ Relman, *supra* n. 102, at 237.

the needs of the community, respond to conflicts between interested parties, and tackle new bioethical problems. The courts, on the other hand, will still be able to protect patients' rights if they are dissatisfied with the results of the HEC recommendations. Furthermore, patients, courts, and HECs alike will know what sort of process to expect and how to prepare. When these benefits are combined, they create an efficient and sensitive process for resolving end-of-life dilemmas.

CONCLUSION

HEC consultations present a space where alternative modes of bioethics decisionmaking can be tested. The legal profession and the field of bioethics have long adhered to principalist approaches to decisionmaking. These approaches have powerful and often unarticulated influence both within their respective fields and beyond. This influence has already infiltrated HEC decisionmaking and this thesis has argued that principalist approaches to end-of-life decisionmaking are not the best way for HECs to serve all patients. Feminist scholars have challenged both legal and bioethical principalism and have offered alternative strategies for end-of-life decisionmaking.

This thesis has primarily focused on the work of feminist bioethicists and feminist legal theorists in challenging the primacy of principalism and in order to provide a glimpse of what an alternative approach to decisionmaking might look like. MacKinnon has directly challenged principalism in the law with strong language that attempts to incite controversy.³⁰⁴ Minow has thoroughly explained the effects of reliance on neutral principles.³⁰⁵ Sherwin has summarized some feminist bioethicists' discomfort with Beauchamp and Childress's principle of respect for autonomy.³⁰⁶ Roberts has shown how an imbalance of power in health care has been allowed to negatively affect the lives of women of color; she has suggested that we begin from the perspective of women of color to remedy the imbalance.³⁰⁷ Wolf and Rawlinson have shown how the field of bioethics has ignored feminist contributions to bioethical theory and has ignored

³⁰⁴ MacKinnon, *supra* n. 152.

³⁰⁵ Minow, *supra* n. 153.

³⁰⁶ Sherwin, *supra* n. 220.

³⁰⁷ Roberts, *supra* n. 219.

important discourses when other fields have paid attention.³⁰⁸ It is time for the legal profession and the field of bioethics to pay closer attention to what feminists have to offer.

There are other feminist works that would also enhance HEC decisionmaking by breaking them out of the principalist mold. Feminist standpoint theory, for example, has long challenged the possibility of objectivity. Donna Haraway developed the theory of “situated knowledges,” wherein she argues that each of us can only see part of “reality” and we must interpret what we see.³⁰⁹ She describes objectivity as a “...conquering gaze from nowhere...” that is only attainable by the “...unmarked positions of Man and White....”³¹⁰ This translates easily to health care and the legal system, where white men have been the only ones with the power to create knowledge for the last few centuries. The façade of objectivity is a problem for everyone else because all those who inhabit “marked bodies” (e.g., women, people of color) are presumably not represented when knowledge is made. Haraway’s solution is to approach knowledge-making from an embodied and partial perspective.³¹¹

Patricia Hill Collins explains feminist standpoint theory in a slightly different way.³¹² She describes standpoint theory as a way to analyze how power relations create knowledge.³¹³ A standpoint, then, refers to a “historically shared, *group*-based” location

³⁰⁸ Wolf, *supra* n. 217; Rawlinson, *supra* n. 236.

³⁰⁹ Donna Haraway, *Situated Knowledges: The Science Question in Feminism and the Privilege of Partial Perspective*, 14 *Feminist Studies* 575 (1988).

³¹⁰ *Id.* at 581.

³¹¹ *Id.* at 592.

³¹² Patricia Hill Collins, *Comment on Hekman’s “Truth and Method: Feminist Standpoint Theory Revisited”*: Where’s the Power?, 22 *Signs* 375 (1997).

³¹³ *Id.* at 375.

in a power hierarchy.³¹⁴ For example, “women” can be considered a group or standpoint that is at a different location in a power hierarchy than “men.” In the context of health care, this means that women as a group will experience the health care system differently (with greater struggle) than men because they occupy a lower standpoint in the health care power hierarchy. This does not mean that all women’s experiences of the health care system will be the same.³¹⁵ Instead, social conditions have shaped the group and the location from which the group experiences power while individuals members of the group continue to have widely varying experiences as individuals. Patients would benefit if HECs took standpoint into account when analyzing bioethical dilemmas because it would provide information about the power hierarchies that affect patients before and after they enter the health care system with a major medical issue.

As shown in Chapter One, HECs may be open to integrating a greater awareness of social context into their practices. HEC members seem to have a genuine interest in serving patients as unique individuals. Although some HECs may systematically employ a principalist approach to decisionmaking, following the lead of academic bioethics or legal theory, many HECs seem to be more interested in patients than principles. This means that there is space to systematically integrate feminist approaches to bioethical decisionmaking in HEC consultations. DeRenzo and Strauss’s consultation model provides one possible way to carry this out.³¹⁶ As long as concerns about the inadequacies of HECs do not lead to the forced (either explicitly or implicitly)

³¹⁴ *Id.*

³¹⁵ *Id.* 376

³¹⁶ DeRenzo & Strauss, *supra* n. 6.

implementation of principalist approaches to decisionmaking, there is room for other feminist ideas to influence HEC decisionmaking as well. In other words, if HECs can retain their flexibility while addressing major concerns about upholding patients' due process rights, HEC consultations present a space for alternative approaches to be tested.

The final task this thesis has undertaken is to devise a relationship between courts and HECs that will preserve HECs' flexibility. The framework for this relationship is described in Chapter Three. The framework has shown how it is possible to uphold patients' due process rights while attempting to minimize the stress that accompanies litigation, especially at such an intensely emotional time. Courts will benefit from the framework because they are ill equipped to make difficult end-of-life decisions and because they are familiar with the legal standards for deferring to agency decisions. HECs will benefit because they will gain clarity as to their responsibilities in relation to the legal system and they will be able to retain their flexibility in approaching bioethical decisionmaking. Finally, and most importantly, patients will benefit from the framework. If HECs use their flexibility to employ feminist approaches to decisionmaking, HEC consultations will consider the social context of patients' lives instead of analyzing patients' situations using hegemonic principles. Whether or not HECs choose to employ feminist approaches, the framework will ensure that patients' due process rights are upheld by making HECs more accountable and by providing a clear path to vindicating those rights if HECs fail to uphold them.³¹⁷

³¹⁷ Similar concerns about upholding due process rights can be found in alternative dispute resolution literature. Because hospital ethics committees would fall under the larger category of alternative dispute resolution (because it is outside the bounds of the judiciary), the

Overall, this thesis considers HECs a valuable part of the U.S. health care system. HECs occupy a unique place within the health care system and in relation to the legal system. This place is often hard to pin down and has been contested, but it remains a place where innovative approaches to decisionmaking can be tested. Just as states provide a “laboratory” where new ideas can be tested before nationwide implementation (as often reiterated by Justice Sandra Day O’Connor), HECs are also laboratories for creating new approaches to bioethical decisionmaking.³¹⁸ It is the hope of this thesis that at least some HECs will experiment with feminism.

ADR literature may also be helpful for HECs to consider. *See e.g.*, Steven Banks, *ADR and Litigation Involving Social Problems*, 35 *Fordham Urb. L.J.* 109 (2008); Ryan Au & Elizabeth Kent, *The Effect of ADR on the Legal System: A Long-Term View*, 11 *Haw. B.J.* 6 (2007); Robert W. Fairchild & Arthur J. Thompson, *Will the Legal Profession Ever Be the Same? Disappearing Trials and ADR in Kansas*, 76 *J. Kan. B. Assn.* 18 (2007).

³¹⁸ Justice O’Connor is known for often pointing out that states are laboratories for new legal solutions. Her most recent mention of this idea is in *Gonzales v. Raich*, 545 U.S. 1, 42 (2005) (O’Connor, J., dissenting) (“This case exemplifies the role of States as laboratories. The States’ core police powers have always included authority to define criminal law and to protect the health, safety, and welfare of their citizens.”).

APPENDIX A: DeRENZO AND STRAUSS CONSULTATION MODEL

This is the short form of DeRenzo and Strauss's Feminist Model of Clinical Ethics Consultation, intended for HEC use during consultations.³¹⁹

1. *Salient Features*
 - a. Talk with all relevant participants.
 - b. Learn about the patient's present, past, and future medical status, perceptions, and aspirations. This includes medical experiences of persons important to the patient.
 - c. Gather relevant psychological information.
 - d. Gather relevant socioeconomic information.
 - e. Identify any potential for discrimination or stigmatization.
 - f. Articulate the power dynamics of the case.

2. *Framing the Conversations*
 - a. Identify the full range of values, and which values are held by whom.
 - b. Review any similar case from within the institution.
 - c. Identify relevant legal and institutional policy considerations.
 - d. Consider possible sources for negative residual.

3. *Negotiating the Charted Course*
 - a. Negotiate several ethically permissible options.
 - b. Organize the list from a patient-centered perspective.
 - c. Choose a course of action, attempting to build consensus.
 - d. Implement the course of action.
 - e. Document, chronicle, and reflect.

³¹⁹ DeRenzo & Strauss, *supra* n. 6, at 223-224.

APPENDIX B: INTERVIEW QUESTIONS

The following questions were asked of the HEC chair interviewed for the study described in this thesis. The researcher used the same questions to gather information from the published accounts described in Chapter One.

- Can you explain how the committee operates?
 - How often does the whole committee meet?
 - How often are consultations requested?
 - How many members make up a consultation group?
 - How are the consultation groups chosen?
 - Who requests a consultation most often (e.g. physicians patients)?
 - Will you walk me through what happens when someone requests a consultation?

- What are the goals of the ethics committee?
- What are the responsibilities of the ethics committee?
- When was the committee formed at TMC?
- Why the committee was formed at TMC?
- What are the qualifications to become a committee member?
- Is there a training program for new bioethics committee members? If yes, please explain.
- If there is no training program, what sort of guidance do new members receive?
- Do continuing committee members receive any kind of training/education? If yes, please explain.
- If there is training either for new or continuing members, does any of it address the race, gender, or socioeconomic status of patients? If so, how?
- Do you think the race, gender, or socioeconomic status of the committee members influences how they approach problems? Please explain.
- Do you strive to fill the committee with diverse members? Please explain.

- Do you think it would be important to have a committee that represents the makeup of the community in regard to race, gender, socioeconomic status or other characteristics? Why or why not?
- How would you describe the bioethical reasoning methods of your committee as a whole?
- To your knowledge do any of the committee members have formal training in bioethics? How many? Do you? Can you give me details about this?
- What influence do you think the committee has within the hospital?
- What influence do you think committee recommendations have on subsequent judicial decisions?
- What obstacles does the committee face?
- Is there anything else I should know about?

APPENDIX C: SURVEY QUESTIONS

The following questions were asked on a survey given to HEC members at the same institution where the HEC chair was interviewed. For sections A-C, survey participants were asked to indicate their agreement with the statements by using a 5-point scale, where 1 is strongly disagree, 5 is strongly agree, and 3 is neutral. For section D, participants were asked to answer the two open-ended questions. Participants were also asked to provide their occupation, gender, age, and race.

A. Statements about you, as an ethics committee member

1. I draw upon my personal values, beliefs, and background when analyzing a problem presented in an ethics consultation.
2. My gender has an influence on the way I analyze problems presented in ethics consultations.
3. My race has an influence on the way I analyze problems presented in ethics consultations.
4. My occupation has an influence on the way I analyze problems presented in ethics consultations.

B. Statements about the ethics committee

1. Other committee members draw upon personal values, beliefs, and background when analyzing a problem presented in an ethics consultation.
2. It is desirable to draw upon personal values, beliefs, and background when analyzing a problem presented in an ethics consultation.
3. The ethics committee as a whole is representative of the diversity of the community.
4. It is important for the ethics committee as a whole to represent the diversity of the community.
5. Conflicts often arise between committee members in a consultation group.
6. Conflicts between members of a consultation group positively affect the outcome of the consultation.
7. It is desirable to remain neutral when conducting an ethics consultation.
8. It is possible to remain neutral when conducting an ethics consultation.

C. Statements about patients

1. A patient's gender has an influence on the way he/she experiences the health care system, including, for example, hospital stays, interactions with health care professionals, and interactions with insurance companies.
2. A patient's gender has an influence on the way he/she makes health care decisions.
3. A patient's race has an influence on the way he/she experiences the health care system, including, for example, hospital stays, interactions with health care professionals, and interactions with insurance companies.
4. A patient's race has an influence on the way he/she makes health care decisions.
5. A patient's economic class has an influence on the way he/she experiences the health care system, including, for example, hospital stays, interactions with health care professionals, and interactions with insurance companies.
6. A patient's economic class has an influence on the way he/she makes health care decisions.
7. I often encounter situations in ethics consultations where the patient's choice conflicts with the doctor's medical advice.
8. In a situation where the doctor and patient disagree on the best course of treatment, I think the doctor's opinion is more important.
9. In a situation where the doctor and patient disagree on the best course of treatment, I think the patient's opinion is more important.
10. Patients have insights into their medical situations that doctors do not have.

D. Please answer the following questions in the space provided. If you need more space, please use page 6 of this survey.

1. Describe your personal approach to the bioethics consultation.
2. Describe the formal bioethical theory, if any, that informs your approach to the bioethics consultation.

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