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End-of-life Care Practices in Two Cultures: A Comparative Ethical Analysis and Recommendations

Nora Alharbi

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END-OF-LIFE CARE PRACTICES IN TWO CULTURES: A COMPARATIVE ETHICAL ANALYSIS AND RECOMMENDATIONS

A Dissertation
Submitted to the McAnulty College and Graduate School of Liberal Arts

Duquesne University

In partial fulfillment of the requirements for
the degree of Doctor of Philosophy

By
Nora Al Harbi, MHA

August 2018
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Approved April 19, 2018

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ABSTRACT

END-OF-LIFE CARE PRACTICES IN TWO CULTURES: A COMPARATIVE ETHICAL ANALYSIS AND RECOMMENDATIONS

By

Nora Al Harbi, MHA

August 2018

Dissertation supervised by Professor Henk ten Have

This dissertation examined the similarities and differences between the end-of-life care strategies employed in the United States and Saudi Arabia. End-of-life care has emerged in recent decades as a medical practice specialty. It has taken on enhanced significance in the United States in tandem with the aging of the Baby Boomer generation, but it is also a significant focus of practice and research in other countries as well. In the context of Saudi Arabia, however, end-of-life care is still very much an emerging phenomenon that is being shaped and informed by Saudi culture, tradition and the Islamic faith.

This study compares and contrasts the approaches taken to end-of-life care in the United States and Saudi Arabia. It is essential a case study using two cases. It moves from an assessment of the state of such practice in the United States to a point-by-point analysis of how such aspects of end-of-life care as delivery of palliative care, hospice care and end-of-life
counseling are addressed in each country’s medical system. Issues of how physicians in each context approach the questions raised by perceived futility of treatment, informed consent, patient and family education, decision-making, withdrawal and withholding of care, and Do Not Resuscitate/Advanced Directives/Living Wills are explored.

The study demonstrates that whereas end-of-life care practices in the United States are an artifact of a strong focus on patient autonomy, in Saudi Arabia physicians are more likely to make decisions on behalf of their patients. Culture and religious influences in the form of Islam and its mandatory submission to the will of God are the dominant influences operating in the Saudi medical system, which nevertheless emphasizes the ethics of benevolence, non-maleficence, and compassion. The study concludes with a recommendation that the Saudi system be modified to provide greater emphasis on patient education and participation in end-of-life decision making.
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Chapter One

Introduction

A. Background of the Problem

Terminal illnesses have become prevalent in many societies around the world. Several reasons have contributed to this development including the pervasiveness of chronic illness and increased life expectancy. These conditions include cancer, arthritis, diabetes, stroke, and heart disease. Some of these conditions become fatal when diagnosed late or when not managed effectively. Similarly, life expectancy has increased in all parts of the world. While some people remain healthy during old age, it is more probable for older people to live for two or more years with a chronic disease and undergo substantial disability before dying. The concept of end-of-life care has expanded its significance due to the prevalence of terminal illnesses. While the development of end-of-life care has introduced substantial benefits, it has also raised critical ethical issues. These issues include withholding or withdrawing treatment, dignified death, application of euthanasia, end-of-life sedation, role of research and futile treatment. These ethical issues have spawned contentious debates among scholars and motivated studies into issues related to end-of-life care.

The issue of dignified death has raised a contentious debate in different settings. On one side, scholars argue that patients have to be given the right to die in a dignified manner. On the other hand, it has been argued that humans have no obligation to determine how people should die. This debate has also raised questions concerning the role of the health care system and caregivers. In his book, Hester notes that people often colloquially define the goal of healthcare as preserving life and avoiding death. According to Hester, this definition is too narrow and
does not capture the essence of end-of-life care. Consequently, Hester proposes that the goal of medicine should be to help people live healthily. This proposal implies that it is not the aspiration of healthcare to prolonging the life of the patient without improving the quality of life. This goal captures the calling of medical practitioners and the interest of the patient.

Because of the fundamental ethical perspective shared by physicians regardless of their nationality or culture, one would anticipate that physicians across the globe would have embraced the concepts of palliative care and pain treatment. However, as this discussion will demonstrate, in a number of regions in the world, palliative care is poorly understood despite the fact that the rate of life threatening conditions in such regions is comparable to that of others where palliative care is commonplace.6

Palliative care is increasingly entrenched in Western societies but even in these societies, death has become medicalized and cure rather than palliative care is often emphasized in part because there can be a lack of acceptance of death which in turn leads to reluctance in seeking end of life care. That said it is also important to note that in Islamic societies, most people acknowledge the inevitability of death and are perhaps somewhat more acculturated to its inevitability. Even though this is the case, palliative care programs have been revealed as relatively scarce in Middle Eastern countries in general and in Saudi Arabia in particular.7

Part of the problem is that there don’t appear to be any established government supported guidelines in Middle Eastern countries that address questions of palliative care and even of end of life care protocols. The intersection of religion and medical practice in countries like Saudi Arabia may be at least partially responsible for this deficit. Medical service providers in Muslim
majority countries tend to organize their guidelines around tenets of the faith rather than bioethics per se.\textsuperscript{8}

Hester does note that in Western countries, those medical institutions that are owned and operated by religious organizations or faith communities may bear more relationship to Muslim institutions than has previously been acknowledged. Such hospitals, including those that are owned and operated by various Catholic organizations, Protestant faiths, and so on may also have guidelines for care delivery that are outside of the bioethical norms accepted in other Western medical institutions. What this means, according to Hester, is that one neither can nor should be overly hasty in generalizing assessments of “all” Western or American medical institutions and their practices.\textsuperscript{9}

The issue of withholding and withdrawing treatment has also raised contentious debates concerning how patients express their wish to have treatment withdrawn, and the criteria used to differentiate ordinary and extra-ordinary treatment, and the criteria used to determine the competency of patients.\textsuperscript{10} Some healthcare setting permit patients to express their wishes to withdraw from futile treatment using advance directives while other do not. In some setting, only medical practitioners can determine the futility of treatment. The issue of withholding and withdrawing treatment also raises ethical issue concerning medical practitioner’s duty of care, distinction between acts and omissions. Different healthcare setting apply different values in addressing these ethical issues. In most cases, end-of-life decisions enmesh moral, religious and cultural factors that are dominant in a given setting.\textsuperscript{11}

There is an extensive body of literature that has explored ethical issues associated with the end-of-life care from the western perspective. In the United States, the concept of end-of-life
care has been largely secularized hence placing a lot of emphasis on autonomy of the patient. Practitioners often address ethical issues in end-of-life care from the perspective of the four principles of bioethics. These principles include respect for patients’ autonomy, beneficence, nonmaleficence, and justice. In the United States, many bioethicists advocate for respect for patient autonomy in end-of-life care. They argue that patient’s views and wishes should be taken seriously by the community as well as the medical profession. Patients should, therefore, be involved in making significant decisions concerning their care.

In Saudi Arabia, the case is different since the healthcare context is influenced by a different cultural orientation, which favors communitarianism, patriarchy, and personal relationships as opposed to individualism. In addition, the healthcare context in Saudi Arabia and other Middle East countries has been largely influenced by the Islamic religion. Saudi Arabian people have different views concerning why people live and how they die. Therefore, end-of-life care is approached from a significantly different perspective. Saudi Arabia’s end-of-life practices place significant emphasis on values such as sanctity of life, personal relationships, family involvement in decision-making, patriarchy, and compassion among others. Some of these values conflict with western bioethical principals such as patient autonomy. The emphasis on personal relationships, sanctity of life, patriarchy, and compassion places constraints upon individual decision-making and patient autonomy. There is a knowledge gap in regard how end-of-life care can be improved without compromising religious and cultural principles. The present research compares end-of-life practices in Saudi Arabia and U.S.A. with the aim of identifying constraints placed upon individual decision-making and patient autonomy by the Saudi Arabian culture, and recommending ways of overcoming these constraints without compromising essential religious and cultural principles.
Scholarly bioethical literature emphasizes the need to develop end-of-life care systems and practices that are sensitive to different cultures.19 It is in the light of this view that the current research seeks to explore cultural elements in Saudi Arabia that influence end-of-life issues and how best-practices can be incorporated without seriously compromising religious and cultural values. Specifically, the dissertation seeks to enhance end-of-life practices by ameliorating or adapting some of the constraints placed upon individual decision-making and the exercise of autonomy. While the principle of patient autonomy has worked well in North America, there is a need to establish the best way of incorporating this principle in the Saudi Arabian context. There is also a need to explore alternative concepts of ethics because the emphasis on respect for autonomy may isolate other relevant issues such as dependency, fragility, and vulnerability.20 Similarly, prioritization of respect for individual autonomy may contradict the interests of families and society, which is highly emphasized in collective cultures such as Saudi Arabia. The current study will examine these issues.

B. Thesis Statement

In six chapters, the argument is advanced that since culture, more so than religion, has shaped the end-of-life care practices in Saudi Arabia, it is ethically justified to enhance these practices by ameliorating some of the constraints placed upon individual decision making and the exercise of autonomy. Patient autonomy is a critical ethical principle in the health care context. This principle is concerned with ensuring that patients chose what they want, and giving them the chance to articulate their choices and having people respect those choices and act on them.21 It focuses on ensuring that patients have access to resources and information that is necessary to make informed decisions. Beauchamp and Childress defined autonomous decisions as “decisions that patients make intentionally and with substantial understanding and freedom
from controlling influences.” Medical practitioners need to respect patients’ autonomy by providing patients with vital medical information and encouraging them to participate in making decisions concerning their treatment.

This thesis reflects an understanding of the ways in which culture impacts upon the delivery of medical care throughout the lifespan. It further should be understood as inclusive of the influence of religion. This does not mean that religion is the sole determinant of what comprises a culture. Culture is certainly inclusive of history, traditions, values, beliefs about individuals and society, the role and influence of government, and the effects of the environment.

It is not the purpose of this dissertation to offer a point by point comparison of the cultures of the United States and of Saudi Arabia. Culture is discussed herein insofar as it relates specifically to the delivery of end of life medical care. The thesis that is addressed is cognizant of the enormous influence of culture in this context. It is also cognizant of the reality of Saudi Arabian culture as highly traditional, conservative, resistant to rapid change, and essentially authoritarian, patriarchal, and collectivist. When these characteristics are found in tandem with a faith that emphasizes the decisive role of the Supreme Being in shaping man’s destiny, the results can be immediately recognized. It is these results that are identified herein.

The above thesis statement is relevant to the modern healthcare landscape and congruent with the educational goals of the current medicine and nursing programs. Literature shows that there are substantial discrepancies in how the U.S. and the Saudi Arabian end-of-life systems approach end-of-life issues. The principle of respect for patients’ autonomy is deeply entrenched in the U.S. end-of-life practices. Patients’ views concerning their care during end of
life are highly respected. However, cultural elements within Saudi Arabia have placed a high value on the sanctity of life, compassion and dependency at the expense of the patient’s right to choose the intervention that he or she will receive during the end-of-life stage. However, existing body of literature does not point out how these differences can be reconciled especially in relations to the ethical principle of patient’s autonomy. The principle of patient autonomy goes hand-in-hand with values such as truth telling, privacy, fidelity and confidentiality. These values are least emphasized in the Saudi end-of-life care context. This dissertation contends that it is possible to integrate US practices relating to decision-making and autonomy into the Saudi end-of-life practices without comprising essential cultural and religious values.

Strengthening the principle of patients’ autonomy in the Saudi’s end-of-life care practices will strengthen the Saudi Arabian system in various ways. First, respect for patient autonomy will enhance the quality-of-life of the patient by respecting his or her right to self-determination. This principle encourages healthcare practitioners to look beyond the patient’s physical wealth and consider other relationships and environmental factors that contribute to well-being of the patients. It is not the aspiration of healthcare to prolonging the life of the patient without improving the quality of life. Secondly, respect for patients’ autonomy will enhance the relationship between the patient and medical practitioners. Close cooperation between the patient and medical practitioners is paramount in end-of-life care. Respecting patients’ autonomy cultivates a relationship of trust and understanding between the patient and medical practitioners. It creates a relationship of mutual respect between physicians and the patient. This relationship, in turn, guarantees cooperation and increases chances of obtaining positive health outcomes.
C. Ethical Issues

Those who support legalization of physician-assisted suicide or euthanasia argue that the right to choose death over a painful, lingering final illness or a condition for which no cure exists is a basic human right. Healthcare givers have a duty to ameliorate pain and suffering, it is argued, and there are cases in which this may require agreeing to allow a competent adult patient to choose death over a prolonged period of suffering. Supporters do caution that the individual requesting such assistance must be mentally and psychologically competent to make such a decision. The responsibility of the physician is perceived as focused on ending rather than prolonging suffering.28

Opponents of this practice argue that the decision to terminate one’s life is often influenced by temporary mental anguish or despair and that such a decision must be carefully considered in light of all the circumstances of the patient (Seale, 2008). The Hippocratic Oath requires that first, physicians must do no harm; aiding the suicidal patient results in harm that cannot be remedied. Many physicians argue that palliative medical care can reduce the pain and suffering of the individual who is terminally ill or afflicted with a condition that can be improved upon.29 These are critical ethical issues that physicians in every country must address as they move forward in providing end of life care to terminally ill patients.

D. Methodology

The methodology of this dissertation entails analysis of the literature on topics related to end-of-life care in U.S.A. and Saudi Arabia. The researcher engages literature in areas such as western bioethics, Islamic bioethics, end-of-life care, palliative care, and intensive care. Based
upon a comprehensive review of the literature, the study functions as a comparative ethical analysis where the researcher compares end-of-life practices in the United States and Saudi Arabia from an ethical perspective. Comparative analysis was the most suitable design for this study as analysis of actual practices within their context enabled the researcher to get an in-depth comprehension of complex issues associated with the end-of-life care. Comparing the United States and Saudi Arabian end-of-life practices also made it easier for the researcher to identify gaps with the Saudi system in relation to issue of patient autonomy. The researcher studied end-of-life care approaches within the U.S. and Saudi contexts, and made comparisons in order to bring out differences. Comparative analysis also enabled the researcher to learn from concrete success concepts within the United States and craft recommendations that will lead to the improvement of Saudi’s end-of-life care.

The goals of the dissertation include comparing (a) the U.S.A. and Saudi Arabian end-of-life practices, (b) comparing U.S.A. and Saudi Arabian intensive care practices, (c) comparing U.S.A. and Saudi’s palliative care practices, and (d) recommending ways of incorporating elements of the U.S.A. end-of-life practices in the Saudi Arabian context. Although no empirical data is gathered, the researcher makes wide use of empirical data from scholarly studies to generate theoretical arguments that justify the thesis. The use of empirical data from secondary source was a more practical method given that the scope of the study entails comparing two vast countries that are separated by a lengthy geographical distance.

The publications used in this research were retrieved using many databases CINNAHL, Medline, Medscape, Google scholar and Pub Med. The terms/phrases such as “end-of-life care”, “palliative”, “western bioethics,” “Islamic bioethics,” were used to search for articles and books. No authors’ names or specific journals were requested. The review of scholarly studies,
unrestricted by year, did not yield any work that compares ethical practices in the U.S. and Saudi Arabia end-of-life care. However, the search process led to identification of publications that address issues related to the current dissertations such as end-of-life care practices in the U.S., end-of-life care practices in Saudi Arabia, intensive care practice in the U.S and Saudi Arabia and others.

This study falls under the rubric of what is known as Small N comparative case research defined by Dooley as “an inquiry investigating a contemporary phenomenon within its real-life context, when the boundaries between phenomenon and context are not clearly evident; and in which multiple sources of evidence are used.”30 This research methodology employs a small sample of cases as opposed to focusing on a single case or considering a broader sampling of cases. Small N comparison does not seek generalization or prediction but as has been noted, tends to emphasis a well-defined interest in order to understand it completely and to observe the ways in which individual variables interact. Such a strategy gives a researcher the opportunity to use both primary and secondary source material but does not require that new data be generated via statistical methodologies.

Lange conceives of Small N comparative research methods as capable of expanding insight into complex phenomena.31 This research strategy is particularly useful in that it allows a researcher to acquire insight into social and other issues that are subject to the influence of change and volatility. Additionally, this strategy helps to facilitate the development of conclusions derived from case comparisons which take on new interest because the cases themselves share similar characteristics.
Essentially, as Lieberson suggests, Small N case studies are designed to compare and contrast cases that do share some basic and even fundamental characteristics. In the present instance, for example, both the Saudi Arabian and United States healthcare systems exist solely for the purpose of delivering medical and related services to a well-defined client group.\textsuperscript{32}

The work of such a research project is essentially interpretive, seeking to account for similarities and differences that can be observed when two, three, or perhaps even four individual cases are considered. The systematic analysis of differences and similarities leads to a close comparison of the individual phenomenon or the institutions that are being examined. The emphasis in such studies is on description rather than inferential statistical analysis.

Lieberson said that Small N studies assume deterministic as opposed to probabilistic approaches.\textsuperscript{33} Questions that are addressed in such studies focus on why, how, and when. These cases are compared to determine the ways in which similar or identical issues are addressed by different entities or in differing but nevertheless similar situations. One might, for example, study the ways in which two different countries pursue development of their industrial sector, the ways in which two or three different banks cope with a recession, or the ways in which medical care delivery systems in two very different countries focus on end of life care.

Researchers including Baxter and Jack argue that Small N and other case studies should be considered by a researcher when: 1) the focus of the study is on developing answers to how and why questions; 2) the behavior of individuals or institutions cannot or should not be manipulated; 3) the goal is to identify contextual conditions relevant to the phenomenon under study or boundaries are not clear between the phenomenon and the context in which it occurs.\textsuperscript{34} The methodology is therefore particularly useful when the researcher is interested in assessing
how and why a particular institution acts as it does or chooses specific strategies in response to issues that it must address. It can help to identify those factors that influence the decisionmaking that goes into establishing policies, procedures and guidelines.

Small N comparative studies are particularly useful in both qualitative exploration of a phenomenon and a qualitative explanation of that phenomenon. Such studies facilitate explanation of the often complex relationships that exist between dependent and independent variables. In the present study, the independent variables consist of the country itself (i.e., Saudi Arabia and the United States) and the culture of each country. The dependent variables all speak to the ways in which the medical systems of the two countries respond to issues of aspects of end of life care. These issues include ICU use, futility of treatment, palliative care and hospice, withdrawing and withholding treatment, and so on.

The following figure identifies the key variables and their components.

**Variables Addressed in the Study**

<table>
<thead>
<tr>
<th>Independent Variables</th>
<th>Components</th>
</tr>
</thead>
<tbody>
<tr>
<td>Nationality</td>
<td>U.S. vs. Saudi Arabia, Culture, Medical System</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Dependent Variables</th>
<th>Components</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Autonomy</td>
<td>Do Not Resuscitate Orders, Advanced Directives, Living Wills, Informed Consent</td>
</tr>
<tr>
<td>Withdrawing/Withholding</td>
<td>Decisionmakers, Policies</td>
</tr>
<tr>
<td>Palliative Care/Hospice</td>
<td>Opioid Use, Death with Dignity</td>
</tr>
</tbody>
</table>
Futility of Care

Physician Authority

Religious Perspectives on Death and Dying, Authoritarian Orientation

These variables are also impacted by such extraneous or compounding variables as the existence (or lack thereof) of governmental or professional regulations influencing the delivery of end of life care. They are also influenced by patient knowledge and the level of medical education made available to patients by their caregivers. Subsequent chapters of this study address these variables in-depth. It should be noted that as is often the case, these variables tend to overlap. For example, perceptions of the futility of care or a specific intervention are directly linked to decisions regarding withdrawing or withholding treatment.

The value of the Small N study is that they use reasoning in case selection, determination of variables, and the use of inductive and deductive logic. These studies allow both cross-case and within-case analysis. In this context, the present study uses an explanatory approach in a comparative framework. It explores the differences within and between cases to draw comparisons between the cases and to facilitate the replication of findings.

As Lange put it, “within case methods pursue insights into the determinants of a particular phenomenon” via such techniques as causal narrative, process description, and process tracing. The method is driven, therefore, by narrative analysis. As is evident herein, such a method involves the assessment of a broad array of primary and secondary sources in order to capture a comprehensive set of commentaries and assessments. It allows for analysis of common structural and institutional factors and a determination of how these factors influence the delivery of services as is found in the two medical systems being assessed herein.
This, then, is the methodology to be employed herein. It is fully appropriate for a comparison of two different approaches to providing end of life care to patients, who clearly comprise a vulnerable population and who consequently have a right to expect that their medical caregivers will treat them with respect, compassion, and sensitivity. The study does have the potential to enhance understanding of the differences between two similar but nevertheless unique medical systems that are ultimately representative of some of the key ethical and moral values and beliefs of their respective countries.

E. Significance of the Study

The present study is significant and useful for a number of reasons. First, and perhaps most significantly, this study sheds light on the ways in which the culture of a country including its religion, its traditions, its social organization, and its ethical norms and mores influences the delivery of medical care in general, and end of life care in particular. The way in which a country’s medical system approaches the end of life can clearly be seen as saying a great deal about its attitudes toward the rights of individuals.

Secondly, the study illustrates the ways in which unique aspects of end of life care come together to create a normative system in which care is defined and understood. The study helps to illustrate the fact that there is no single understanding of the ethical underpinnings of such medical practices as withdrawing or withholding care, the use of opioids to reduce unavoidable physical suffering, or even larger questions such as the legitimacy of physician assisted suicide or euthanasia.
Third, the study does serve to illustrate the viability of the Small N case study methodology. This research strategy, though limited by the fact that it does not provide for the generation of new statistical data, at least in the present case, nevertheless offers an important strategy for comparing and contrasting different cases which have common elements.

Finally, the study is significant in light of the fact that as Saudi Arabia moves forward in developing its medical system and modernizing many of the practices of that system, issues related to death and dying will certainly become more and more prominent. Research indicates that Saudi Arabia is investing substantially in expanding and modernizing its national medical infrastructure. This will certainly require that questions regarding end of life care as discussed herein be addressed.

F. Limitations of the Study

The present study is constrained by a set of limitations which do inhibit but do not preclude generalization of findings. The Small N comparative case study is limited by the size and number of cases that are considered and the capacity of the researcher to identify materials that are relevant to the variables which have been recognized as encompassing both similarities and differences between the cases. The method is further limiting because, though capable of explanation, it does not generate any statistical data which researchers use to confirm qualitative assessments.38

Another limitation revealed as the researcher was collecting research via targeted online database searches speaks to the question of publication availability. Many of the references specific to the medical system in Saudi Arabia are available only in Arabic language publications.
and while the researcher is fluent in both English and Arabic, the lack of such materials effectively prevented them from being used because their contents could not be verified. That said, however, it was ultimately revealing that the literature was actually quite extensive and more than adequate to the task at hand.

Despite these limitations, the present study does offer a unique opportunity for comparing two cases in which medical practitioners are deeply concerned about the delivery of end of life care to their patients. There is no doubt that physicians in both countries, as will be revealed herein, are equally committed to providing the highest possible standard of care to their patients and ensuring that those patients are ushered into the afterlife with a minimal amount of unnecessary pain and suffering.

G. Definition of Key Terms

Several terms require definition. These are:

**Bioethics:** a field of study concerned with the ethics and philosophical implications of certain biological and medical procedures, technologies, and treatments, as organ transplants, genetic engineering, and care of the terminally ill.

**Euthanasia:** A doctor is allowed by law to end a person's life by a painless means, as long as the patient and their family agree.

**Assisted suicide:** A doctor assists a patient to commit suicide if they request it.

**Voluntary euthanasia** is conducted with consent. Voluntary euthanasia is currently legal in Belgium, Luxembourg, The Netherlands, Switzerland, and the states of Oregon and Washington in the U.S.
**Involuntary euthanasia** is euthanasia is conducted without consent. The decision is made by another person, because the patient is unable to make the decision.

**Passive euthanasia** is when life-sustaining treatments are withheld. The definitions are not precise. If a doctor prescribes increasing doses of strong painkilling medications, such as opioids, this may eventually be toxic for the patient. Some may argue that this is passive euthanasia. Others, however, would say this is not euthanasia, because there is no intention to take life.

**Active euthanasia** is when someone uses lethal substances or forces to end a patient's life, whether by the patient or somebody else.\(^39\)

**Palliative** medicine is a medical subspecialty provided by doctors who offer palliative care for people who are seriously ill. Palliative care relieves suffering and improves quality of life for people of any age and at any stage in a serious illness, whether that illness is curable, chronic, or life-threatening.

**Hospice care** focuses on a person’s last six months of life or less. When curative treatment is no longer an option, hospice professionals work to make the patient’s life as comfortable as possible. This means that hospice care includes palliative care, because the goal is to make the patient as comfortable as possible for the time that’s left.

**Living Will**: A living will is a document designed to control certain future health care decisions only when a person becomes unable to make decisions and choices on their own. The person must also have a terminal illness (the patient cannot be cured) or permanent unconsciousness (often called a “persistent vegetative state”). State laws vary, but they usually allow doctors to stop trying to prolong life when these things happen. If a person has hope of recovery, the living will generally does not apply.\(^40\)
**Do No Resuscitate Order**: A “Do Not Resuscitate” or DNR order means that if you stop breathing or your heart stops, nothing will be done to try to keep you alive. A DNR order allows natural death and is sometimes called an “Allow Natural Death” order. If the patient is in the hospital, he/she or a family member/guardian can ask the doctor to add a DNR order to the medical record.41

**H. Outline**

The dissertation proposes that it is possible to incorporate elements of the U.S.A. end-of-life practices in the Saudi Arabian system especially those relating to patient autonomy and decision-making without compromising Islamic laws and Saudi culture. The chapters of this dissertation are organized to support this argument effectively.

Chapter two discusses the background of the U.S.A. end-of-life practices highlighting the legal and moral views that form the basis of these practices. The chapter will include a brief history of end-of-life care in the United States and how it has evolved over the years. The chapter also discusses legal and moral views that inform end-of-life practices including patient autonomy, dignity for human life, justice, dignified death, futility of treatment, and quality of life.

Chapter three discusses the Saudi Arabian Culture and Islamic Law and explains how these, particularly culture, have shaped end-of-life care practices. The chapter discusses Islamic and cultural principle that guide moral issues including the sanctity of life, life as a gift from God, and the view that death is inevitable. The chapter also analyzes the end-of-life practices in the country, and how cultural and Islamic principles have shaped these practices. The researcher
highlights the constraints that the system places on patient autonomy and decision-making and underscores the importance of overcoming these constraints.

Chapter four will compare intensive care systems in U.S.A. and Saudi Arabia, and explain why elements of the U.S. system need to be incorporated in the Saudi Arabian system. The chapter discusses the major ethical decisions and ethical dilemmas that practitioners have to deal with in this setting including allocation of scarce resources, withholding/withdrawal treatment, physician assisted suicide, difference between killing and allowing to die, criteria of determining patient competency, and type of treatment and intervention. The researcher also discusses the principles and values that practitioners use to guide their decisions in both systems and highlights the limitations that the Saudi’s system places on patient autonomy.

Chapter five will also compare the palliative care practices in U.S.A. and Saudi Arabia and highlight the benefits of incorporating parts of the U.S. system into the Saudi Arabian system. The chapter discusses the ethical decisions and issues that practitioners in this setting have to tackle including the management of pain, medical futility, the use of advance directives, and withholding/withdrawal treatment among others. The chapter also examines the principles that both systems use to tackle these ethical problems and identify the constraints that the Saudi palliative care system places on patients’ autonomy and decision-making. The researcher explains the importance of incorporating elements on the U.S. palliative care practices in the Saudi Arabian context.

Chapter six explains withholding/withdrawal practices in Saudi Arabia and USA and underscores the importance of integrating some elements of the USA system into the Saudi system. The chapter examines major ethical issues that surround withholding/withdrawal
decisions including the criteria for determining the futility of treatment, criteria for determining the competency of patients, and how to deal with incompetent patients. The chapter also examines the principles that are used to address these ethical issues in both the USA and Saudi Arabian context and identifies the constraints that the Saudi practices place on patient’s autonomy. The researcher also explains the importance of incorporating elements of the U.S.A practices in the Saudi Arabian context.

Chapter seven summarizes the content of the study and provides an ethical argument on how elements of the USA end-of-life care system can be adopted with the purpose of improving the Saudi system while maintaining the integrity of Islamic law and respect for Saudi culture. The researcher argues that patient autonomy and decision-making can be incorporated in the Saudi Arabian end-of-life practices by enlightening the public about the benefits of these principles and engaging all stakeholders actively in the implementation of changes.
Chapter Two

Background of the USA End-of-Life Care Practices

A. History of End-of-Life Care

End-of-life care in the United States can be traced back to the 1960s. Before 1960, the medical field focused on saving and extending lives at all costs. The healthcare system was dominated by generations of physicians who viewed death as an enemy, and something to which patients should not surrender. There was a fine line between not giving up and providing patients with futile treatment. Healthcare was driven by the belief that hope drives good care. Consequently, medical practitioners tried to give their utmost so as to keep the hope of their patients alive. The healthcare system encouraged this utopian dream of fighting mortality and aging. Patients and caregivers left decisions concerning treatment to doctors. Medical practitioners administered aggressive treatments to patients even in situations where the patient’s state is irreversible. A large segment of the American citizens were dying in nursing homes and hospitals where they were subjected to medical indignities, deficient pain relief care, and indifference treatment of anxious friends and family members.

The concept of end-of-life care emerged in the 1960s. This concept entails providing “interdisciplinary and supportive services to critically ill persons and their family caregivers that focus on alleviating suffering, facilitating end-of-life wishes and providing support to the bereaved”. It is a component of palliative care that focuses on providing care to patients at the end-of-life stage. The concept of end-of-life care emerged after the medical fraternity came to term with the inevitability of death. Medical practitioners came to accept that death is an inevitable part of humans and other living things. Physicians changed their paradigms from
trying to extend the life of patients at the terminal stage of the illness to focus on improving the quality of life of these patients. End-of-life care focuses on assisting patients to enjoy what life has to offer by decreasing pain and providing emotional and spiritual support. It also extends beyond the death of the patients by seeking to assist family members through the grieving process.

Several events shaped the development of the end-of-life care in the United States. A significant event was the establishment of the first hospice in the nation, the Connecticut Hospice.45 This hospice began its operations in 1974 marking the onset of the hospice and palliative care movement. Giovanni defined palliative care as an approach of boosting the quality of life of patients and their families facing life-threatening illness through the relief and prevention of suffering.46 The concept of palliative care extends the principle of hospice care to the broader population by ensuring that patients facing life-threatening condition receive relief care in the home environment. Palliative care transitions into hospice care when the condition of the patient worsen.47 The hospice and palliative care movement shifted physicians’ attention from curing to providing care when dealing with patients who have irreversible conditions. These two concepts became significant elements in end-of-life care. The two concepts supported physicians’ training in the care of the dying. The creation of these healthcare concepts also encourages an open discussion regarding the issue of death and dying.48 Americans became more willing to accept death leading to better management of suffering.

The concept of palliative care also broadened the distinction between pain and suffering. People came to understand that patient experience other forms of suffering besides physical pain.49 It gradually became clear that palliative care is not just provided in hospices and is not just for patients at the terminal stage of their illness. Another event that shaped the
development of the end-of-life care in the United States was the adoption of the Medicare Hospice Benefit, in 1982. The passage of this law established hospices as vital parts of end-of-life care. The concept of hospice care is anchored on the belief that every person has the right to die pain-free and with dignity.

Another event that shaped end-of-life care practices is the Study to Understand Prognoses and Preferences for Outcomes and Risks of Treatment (SUPPORT). SUPPORT was a five-year study that sought to examine the preferences of patients at the end-of-life stages concerning treatment. The Robert Wood Johnson Foundation sponsored this study after noting that medical practitioners were subjecting patients near the end-of-life to high-cost and high-tech intervention that were ineffective and contrary to the patients’ wishes. The study, which was published in 1995, confirmed that a majority of patients at the terminal stage of their illness were being subjected to ineffective treatment against their wishes. Physicians rarely consulted prognosis data or inquired about patients’ preferences before establishing a care plan. It also established that most patients and families did not understand the treatment options available to them and to articulate their wishes. Results of the SUPPORT study highlighted the need for changes in professional and social norms and catalyzed the establishment of initiatives to improve end-of-life care. These initiatives focused on understanding the concerns of patients and their families, building supporting environment through legal and cultural means, increasing clinical capacity and developing successful models for delivering high-quality end-of-life care.

The establishment of organizations that advocate changes in the American end-of-life care is another event that shaped US end-of-life practices. The Americans for Better Care of the Dying (ABCD) is among these advocacy organizations. ABCD was a non-profit consumer membership organization came to being in 1997, with the aim of assuring quality of care for
patients at the end-of-life stage. The organization helped building momentum for fundamental reforms in the American end-of-life care. It informed the establishment of new methods and shaped public policies regarding end-of-life practices. ABCD experienced financial problems and closed doors in 2008. The Partnership for Caring (PFC) is another advocacy organization that shaped American end-of-life practices. PFC brought together representatives of healthcare organizations and initiatives that were concerned with end-of-life care such as the American Bar Association (ABA) and the Robert Wood Johnson Foundation (RWJF). PFC focused on facilitating advanced care planning among patients at the end-of-life stage assisting them to complete living wills or designate healthcare surrogate. PFC partnered with ABA to publish an annual summary of legislations that affected advanced care planning in various states and ranked each state’s effort to improve end-of-life cares. This initiative brought substantive changes in laws governing end-of-life care. PFC also partnered with RWJF to establish a national program known as the Last Act. The Last Act focused on improving communication and decision-making among healthcare consumers regarding their own deaths, transforming the cultures of healthcare institutions and changing the cultures and attitudes of Americans towards death.

B. Moral Views

The work of human healing has always been associated with ethics. Ethics refers not only to the rules, beliefs and customs of a given society; it also elucidates the scholarly effort to analyze these rules, beliefs, and customs. Jonsen linked the concept of ethics to three major topics; character, duty and social responsibility. The topic of character relates ethics with certain qualities. This ethical practice proposes that a good medical practitioner should exhibit
qualities such as gentleness, discreteness, empathy, and compassion. These qualities attract and keep patients, make them grateful, give them hope, and contribute to the healing process.

The topic of duty relates ethics to defined duties and responsibility. This ethical perspective suggests that a good medical practitioner is one who complies with existing rules and duties. It emphasizes on creating formal code of ethics that make explicit the duties and responsibilities of medical practitioners. The third topic links medical ethics to social wellbeing. This ethical perspective suggests that medical practitioners ought to show themselves as worthy of social trust and authority.

The core principles of medical ethics can be traced back to antiquity. These principles are beneficence and nonmaleficence. The principle of beneficence requires physicians to pursue actions that benefit the sick while the principle of nonmaleficence requires medical practitioners not to do harm in the process of providing medical care. The two principles are congruent with medicine’s main goal of helping the sick regain health and reducing suffering. Other ethical principles have since been introduced including justice and respect for patient autonomy.

The principle of patient autonomy has its origin in analytic and political philosophy. It demands that medical practitioners respect the patient right to decide what treatment option they should receive. This principle is synonymous with the concept of self-determination. Justice Cardozo, in the landmark case between Mrs. Schloendorff and her gynecologist, made the expression that “every human being of adult age and sound mind has the right to determine what shall be done with his body.” Justice Cardozo’s statement best described the principle of respect for patient’s autonomy. The statement identifies two critical elements that make a person qualified to make medical decisions; attaining adult years and being of sound mind.
The principle of justice focuses on ensuring fair allocation of medical resources. The ethical concept of distributive justice suggests that the burdens and benefits of providing medical care should be shared uniformly among all members of the community. Because communities have limited medical resources, existing resources need to be distributed fairly and equally among all members. Distributive justice is necessary for any given system to function effectively as absence of a sense of justice gives rise to conflicts. People begin to challenge the system when they feel that benefits of the systems are not being distributed fairly.

As people enter their end-of-life stage, they, their families and caregivers face a broad array of decisions. These decisions may be spiritual, practical, legal, psychosocial or medical in nature. At the time the concept of end-of-life emerged, Americans were unable to determine the morality of most of the issues that relate to this concept. These issues include withholding/withdrawing treatment, futile treatment, end-of-life sedation, dignified death, and application of euthanasia. The basic stance of U.S law concerning these issues had not been determined. Applying the basic ethical principles of beneficence and nonmaleficence was also difficult especially in making decisions concerning the use of life-sustaining interventions. In some cases, these interventions do not provide significant benefit to patients, but the potential for substantial harm remains. There was also the question of who has the definitive authority to decide the appropriateness of a given intervention; should it be a physician or policy makers? Applying the principle of patient autonomy also became difficult as it gave rise to contentious questions such as whether patients have the right to refuse treatment. It also gave rise to questions regarding the application of the principle to patients who are unconscious. Justice considerations also arose when people began to compare the high cost of administering life-sustaining treatments with the marginal benefits that these treatments provided to the patient. Hospital policies varied and
physicians made decisions on the basis of individual cases. Between 1960 and 1970, the field of bioethics responded to this situation. The field of bioethics was able to reconcile stakeholders’ views concerning most of the issues on end-of-life care. Today, there is a general consensus in law, ethics and medicine concerning end-of-life care issues.

According to David Kelly, the general consensus on end-of-life practices is founded on three pillars. The first pillar is the recognition that not all treatments that prolong life are beneficial to the patient. The second pillar is the recognition of the difference between killing and allowing a person to die. The third pillar is recognition of patients’ right to liberty, privacy, and autonomy.

i. **Medical Futility**

The first pillar recognizes that advancements in the medical field have drastically changed the dying process. Today, there are medical interventions and technologies that can sustain human life even in situations where there is little hope of recovery or little meaning for existence. This pillar calls for the acknowledgment of the fact that not all interventions that prolong life are beneficial to patients. Some interventions are highly burdensome to the patient and his family, make the patient dependent and hamper her or his quality of life. The first pillar calls for a balance between the values of preserving life and patient-centered quality considerations. Medical practitioners are not ethically obliged to provide care that they know will not have a reasonable chance of benefiting the patient. Practitioners are ethically expected to shift attention from intensive care to the provision of comfort and closure when it becomes evident that existing medical interventions have become futile. However, there is a contentious question regarding what constitutes futile treatment. Futile treatment is often understood as
treatment that has no reasonable chances of success. This understanding can, at times, be misleading. For instance, stating that executing a cardiopulmonary resuscitation (CPR) on a patient with a terminal condition is futile does not mean that the CPR would have little chance of success. The term futile means that the CPR would not have a noteworthy impact on the patient’s underlying condition, but it will give the medical practitioners short-term success of sustaining the life of the patient.

The term futility is also wrongly taken to mean useless. A given treatment can be futile and at the same time, useful. For instance, CPR is useful for a person in a persistent vegetative state because it helps restore the cardiac functions of the patient. However, this treatment is qualitatively futile because it does not significantly improve the patient condition but serve to postpone the eventual outcome. The treatment does not restore the quality of life for the patient, which is a significant goal of healthcare. This treatment does not end the patient’s dependence on life support system. Similarly, the term futility includes an element of confidence that the treatment cannot improve the quality of life of the patient. It is more that uselessness. It connotes that the degree of uselessness of the medication has been determined with certitude. It becomes difficult to determine whether a treatment is futile when people are not sure what it means to be futile.

Defining the concept of futility does not solve the problem of applying the concept of futility. Another problem that makes it difficult for medical practitioners to apply this concept is the lack of certainty regarding where this concept should be applied. There are often problems in terms of determining the total net worth of a person. There are also problems in terms of determining who should determine the futility of treatment. People have different conceptions about life. Ethicists have a conception about the value of life that is different from that of
medical practitioners. Therefore, they have a different idea of when a treatment should be considered futile.

The concept of medical futility can be defined in various ways. A significant way entails grouping it into two categories; post-hoc futility and predictive futility. Post-hoc futility refers to treatments that have already been tried and proven to be futile. The futility of treatment is determined retrospectively. Predictive futility refers to treatments that have been envisaged to be futile before they are even implemented. This predication means that the treatment option should not be tried. Predictive futility is further categorized into four types: conceptual futility, physiologic futility, probabilistic futility, and goal futility. Conceptual futility is futility that is based on a given concept such as brain death or persistent vegetative state. In the case of a brain dead patient, a ventilator is considered futile treatment because it cannot bring the life of the patient back. Physiologic futility is also divided into two categories; medical nonsense and medical impasse. Medical nonsense refers to a treatment that doctors can unilaterally consider to be ineffective against a given condition. For instance, a patient asking for antibiotic for a viral respiratory infection may be considered medical nonsense. Medical impasse occurs when a person’s condition makes it physiologically impossible for a sensible treatment to work. For instance, cancer at an advanced stage makes it physiologically impossible for sensible treatments such as chemotherapy and radiotherapy to work. Probabilistic futility refers to treatment that has a very low likelihood of success. Goal futility occurs when the treatment in question cannot provide the goal that the patient would want to pursue. For instance, while a ventilator may help keep a patient who is in a vegetative state alive, this intervention is considered futile because it does not improve the condition of the patient.
The existence of multiple definitions of the concept of futility suggests that futility is a subjective judgment. An intervention that might have been effective at one point may become ineffective as the condition of the patient progresses. Similarly, a treatment option that is affective in one case may be completely futile in another case. Since futility is not a discrete concept with clear demarcations, there cannot be an objective definition of the concept of futility. Consequently, there is a general consensus that decision concerning the futility of treatment should be made on case by case basis at the bedside, and should consider the patient and surrogate’s input.

ii. Ethical Distinction between Killing and Allowing a Person to die

The second pillar proposes that there ought to be an ethical difference between killing and letting a person die. Western bioethics makes a distinction between killing and allowing a person to die. These bioethical principles suggest that while it is always wrong to actively take a person’s life, it is sometimes right to allow a terminally ill patient to die naturally. American bioethics recognizes that it is not always right to allow the patient to die. It is not morally right to allow the patient to die where her or his condition can be easily addressed. Physicians who allow patients to die under such circumstances violate their ethical duty of care. However, some situations justify physicians’ decisions to allow the patient to die. In situations where existing treatment options are burdensome and are of minimal benefit to the patient, it is morally right for physicians to allow the patient to die by withholding or withdrawing life support system. The physician does not do anything beyond withdrawing or withholding extraordinary treatment so as to allow the patient to die naturally. American bioethics does not support the use of active means of bringing the life of patients to an end. It is acceptable to withdraw or withhold treatment and allow the patient to die and never acceptable to execute a deliberate act that leads to the death of
the patient. This ethical distinction condemns the acts of assisted suicide and euthanasia.

Bioethicists who support the concept of physician-assisted suicide deem this distinction as nonsensical. They argue that stopping treatment is a deliberate act that ends a patient’s life; hence, it is no different from administering a lethal drug. A doctor that switches the respirator commits a deliberate act that leads to the death of the patient. Rietjens, Van der Maas, Philipsen, van Delden and van der Heide go further and argue that active killing of the patient is more ethical than letting a patient die because it is quicker and cleaner. The patient dies with less pain and embarrassment.

In many cases, physicians are more comfortable with the act of withholding treatment than with the act of withdrawing treatment. The act of withdrawing treatment is closely associated with the patient’s death. For instance, in a scenario involving a patient in a permanently vegetative state who needs a ventilator, the patient remains alive until the medical practitioner switches off the ventilator. The death of the patient is closely linked with the act of switching off the ventilator. This situation is in a sharp contrast to cases where the ventilator was never used. In such a case, the patient dies not because of the physician action but as a result of the patient’s illness. American bioethics does not make an ethical distinction between withholding and withdrawing treatment. For this reason, the patient is considered to have died of the underlying condition when treatment is withheld or withdrawn.

Medical practitioners have an obligation to withhold this treatment where a patient had prepared an advance directive requiring medical practitioners not to apply mechanical ventilation if she or he was irreversibly incapacitated. There are cases where mechanical ventilation is started before the condition of patient become irreversible or terminal. In such a case, the medical practitioners have an ethical obligation to discontinue the mechanical ventilation once
the condition of the patient becomes terminal and irreversible, and the patient had expressed this wish. In this case, the medical practitioners are not causing the death of the patient but are merely removing an external medical support system that the patient had rejected in advance.

iii. **Respect for patient autonomy**

The third pillar proposes that any medical action should be congruent with patients’ wishes, values, and preferences. It suggests that patients should have control over decisions regarding the use of medical intervention. Competent patients should have the right to refuse or accept treatments that the physician recommends based on the ethical principle of autonomy. The pillar also proposes that when the patient does have the capacity to make decisions, treatment decisions should be congruent with what the patient would want. In the United States, the wishes of patients are communicated through oral or written advance directive. In the absence of elaborate advance directives, the decision-making process is left to surrogates who make decisions based on their understanding of the patient. Family members are ethically empowered to make decisions on behalf of the patient, in situations where the patient has not appointed a surrogate. The pillar also suggests that medical practitioners should facilitate the patient’s decision-making process by promoting open and truthful discussion regarding the patient’s situation and evidence-based medical options. In Western bioethics, adults are permitted to make their own decisions about the kind of medical treatment that they want. Failure to do so amounts to an invasion of individuals’ right to bodily integrity and the right to establish the direction of their own lives.

Religion played a significant role in shaping end-of-life practices in the United States. Theologians were the first to join the bioethics movement in the 1960s. Specifically, Catholic
theology played a momentous role in shaping the bioethical debates. Over many centuries, Catholics had developed a highly specified approach to medical ethics. Similarly, the Jewish tradition has a systematic approach to medical ethics. Catholics and Jews developed detailed studies of healthcare ethics. However, Catholics had a greater influence on the development of the American bioethics than Jewish scholars.

iv. Value of human life

A significant moral issue associated with end-of-life care is the value of human life. There has been a controversial debate regarding the value of human life among American bioethicists. The debates led to the emergence of two schools of thoughts; the sanctity of life perspective and the quality of life perspective. On the one hand, the sanctity-of-life perspective suggests that suitable actions need to be taken in order to save human life. This perspective proposes that life has intrinsic value; hence, every treatment option should be considered if there is a remote chance of saving or prolonging life. This perspective suggests that life is sacred, has infinite value and that the judgment about the quality of life demeans the value of life. Proponents of this perspective argue that the intrinsic value of life presumes the biological existence of a person. They believe that life is priceless, finite and transcendental and, therefore, not rooted in our existence as biological creatures. For a human being to exist, he must be alive and ceases to exist when he dies. The perspective is also rooted in the fact that life is given. Proponents of the sanctity of life perspectives argue that life has intrinsic value because no one chooses to come to existence. One does not choose her or his biological parents or when to come into existence. Proponent of the sanctity of life also suggests that life is beyond all measures such as contribution to society, ability to think and exhibit emotions.
The traditional healthcare ethics was based on the belief that human life is of special worth, a belief that was supported by Christianity.\textsuperscript{65} Catholic theology bases its views of the dignity of human life on biblical stories of creation and redemption. According to these biblical stories, it was the original purpose of God to give humans a special status among all other creatures. In fact, Christianity tells us that human beings were created in the image of God. Thus, according to Christianity, the human person is entitled to respect and is characterized by sanctity.\textsuperscript{66} This view has significant implications in end-of-life care. A significant implication is that life should be prolonged at all costs. This perspective suggests that since life has intrinsic value, medical practitioners should make all attempts to sustain this life. The perspective refutes the idea of futility of treatment because it views life itself as benefit. Since being alive is a benefit, any treatment that prolongs life should be considered beneficial. Another connotation of this perspective is that there is no distinction between killing and allowing the patient to die.\textsuperscript{67} Proponents of this perspective suggest that killing and allowing the patient to die are both immoral acts since medical practitioners need to do all things possible to protect the sanctity of life.

On the other hand, there is the quality-of-life position, which suggests that human life loses all value when certain qualities such as productivity lack.\textsuperscript{68} The quality-of-life position has been examined by Sulmasy, who has highlighted various philosophical views that reinforce the quality of life position. The utilitarian ethical perspective is one of these philosophical views. Utilitarian philosophy suggests that nothing on this world, even life, has intrinsic value.\textsuperscript{69} According to this perspective, what counts as the value of life is the outcome of life. This view has the implication that life has no meaning if a person is unable to live according to certain standards. Another philosophical perspective Sulmasy has used to reinforce the quality-of-life
view is the liberal perspective. The liberal perspective on the value of life emphasizes individual interests, preferences, and life plans. According to the liberal philosophical view, the value of life is something that each person assigns to her or his own life.

The End of Life Taskforce, in their work *Faithful Living and Faithful Dying: an Anglican Reflection of End of Life Care*, supported the quality-of-life position. The taskforce argues that a dying person is not a mere collection of organ systems. The task force advocates for end-of-life practices that serve the patient’s dignity, meaningful identity, and personhood. The quality of life perspective has grave implications on end-of-life care. The quality of life position advocates the cessation of treatment and even active killing. Proponents of this perspective suggest that since the value of a person’s life is determined by the outcome of his life, then any treatment that does not improve a person’s life outcomes should be discontinued or withheld. This perspective asks medical practitioners to weigh the benefits of administering treatments against the burden of the treatment. If the burden of the treatment outweighs the benefits, then the treatment should not be administered.

Catholic theology does not argue in favor of the extreme quality-of-life position. The Catholic tradition recognizes both sanctity-of-life and quality-of-life positions and tries to balance them. It does this by distinguishing between ordinary and extraordinary ways of preserving life. The belief that human beings’ destiny is life beyond the flesh has allowed for a flexible view concerning the issue of prolonging life. This Catholic ideology is largely reflected in American end-of-life practices. American bioethics begins with the presumption that sustaining life is in the best interest of patients. However, ethical principles suggest that this presumption can be overcome by considering factors such as loss of dignity, the level of dependence, amount of suffering, and the degree of humiliations to which certain medical
intervention expose patients at the end-of-life stage. American bioethics has shifted attention from prolonging life to alleviating patients’ suffering when it comes to end-of-life care. Suffering is not just restricted to physical pain but also emotional and psychological distress. Patients at the terminal stage of their illness experience severe emotional and psychological suffering because of their conditions. Some patients do not like the fact that they have become dependent and cannot make meaningful contributions to society. Unlike physical pain, psychological and emotional suffering cannot be eliminated using medications. The American end-of-life system has seen a shift towards the ethics of compassionate care that demands that physicians shift focus from curing the disease to promoting the quality of the patient’s life. This ethics questions the use of medical technologies in situations where the condition of the patient is irreversible.

v. Dignity of the patient

A significant ethical value in end-of-life care entails preserving the dignity of patients. At times, the futile treatments that medical practitioners administer to terminally ill patients are very invasive and demeaning. For instance, a significant way of providing patients with artificial nutrition is through the use of the nasogastric tube. To achieve this, a tube with the size of a pencil is pushed through the nose, down the patient’s throat, and into the stomach.\textsuperscript{73} If the patient is aware and cooperative, he or she may aid the process by attempting to drink water so as to direct the tube to the stomach. If the patient does not do this, the tube may go to the lungs, and the procedure has to begin again. Medical practitioners have to tie the hand of uncooperative patients to the bed rails with one person holding their heads tightly. Another person pushes the plastic tube into the nose. When the tube reaches the end of the nasal passage, the procedure becomes extremely painful as the tube must be pushed hard against the upper part of the throat for it to turn downwards. Sometimes, the tube emerges from the nose or mouth, and the
procedure has to begin again. When the tube reaches the stomach, suctions are applied so as to obtain gastric juice and confirm that it has reached the stomach. If the tube ends up in the wrong place, the patients will vomit when fed causing the vomit to go into the lungs. This scenario leads to the development of aspiration pneumonia. Many uncooperative patients get pressure ulcers because the procedure has restrained them in one position of the bed.

Another procedure entails inserting tubes directly to the stomach through the skin of the upper abdomen, a procedure known as gastrostomy. Gastrostomy is the most frequent technique of artificial feeding because it helps patients to overcome the many problems and discomforts that come with the use of a nasogastric tube. However, there are also challenges in the use of gastrostomy tubes. In normal cases, gastrostomy tubes are inserted under general anesthesia. However, it is often not possible to insert the tubes under general anesthesia in patients at the terminal stage of the illness because most of these patients are too weak to withstand being put to sleep. Consequently, medical practitioners insert gastrostomy tubes when the patient is awake. Only sleep medications such as valium and pain reliever are administered. In order to insert a gastrostomy tube, the medical practitioner asks the patient to swallow a large tube called a gastroscope, which has a light on its end. The doctor looks through the gastroscope to make certain that it has reached the stomach. The medical practitioner pushes the gastroscope against the abdominal wall and stabs the place where he sees the light. The doctor then inserts the gastrostomy tube through the stab wound. The wound remains painful for several days. Some patients are unable to absorb the concentrated feeding leading to episodes of diarrhea. This complication makes the nasogastric and gastrostomy procedure more intolerable to patients.

Another method of artificial feeding entails administering nutrients and fluids through the peripheral intravenous line. A tiny plastic tube or a needle is inserted into a vein, often on the
hand. The method is least invasive but has some risks such as blood clots formation, infection and infiltration of fluid outside the vein. This method also does not allow medical practitioners to administer large amount of protein, sugar and fats, as is the case in nasogastric and gastrostomy feeding. Only low concentration of sugars, fats and vitamins can be administered using this method. The method becomes more painful and uncomfortable when it becomes harder to find the veins. Medical practitioners have to find veins in uncomfortable sites such as neck and legs. In order to overcome this problem, medical practitioners developed a method that uses the central venous lines to administer the feeding. In this method, the plastic feeding tubes are inserted under the collar bone into the bottom of the neck and pushed down to the heart. This method is more risky than the others because there is a high risk of puncturing and collapsing a lung when inserting the tubes. The tubes may also cause life-threatening infections and blood clots. There are also psychological and social costs that come with the use of these feeding methods. In normal circumstances, feedings are social occasions where people come together and share meals. These artificial feeding methods deprive patients of these social needs thus interfering with his or her dignity. The patients’ families also have to incur the heavy financial burden that comes with the administration of artificial feeding.

It is the ethical duty of medical practitioners to ensure that interventions that they administer to end-of-life patients do not undermine their dignity. Medical practitioners need to humanize medical technology by ensuring that they administer them in a way that upholds the dignity of the patient. Humanizing biomedicine does mean that we reject medical advancements but implies modifying biomedicine so as to restore the dignity of physicians and patients. The American end-of-life care recognizes the need to protect the dignity of patients. A significant way of promoting the dignity of patients is by respecting their preferences and
wishes. The wishes, values, and preferences of patients at the terminal stage of the life count when it comes to making decision concerning treatments. Patients are granted the chance to choose their treatment options through oral and written directive. The rights of incompetent patients to choose their preferred medical intervention are preserved through the use of advance directives and substituted judgment. However, the concept of dignity has been pushed to the extent of supporting physician-assisted suicide. Beauchamp and Childress argue that aiding a person to die at his request is a way of showing respect to this person’s autonomous choices. Similarly, refusing to comply with the person’s wishes to end his life is a fundamental disrespect to the person’s autonomy.

vi. Individualism vs. Corporatism

Individualism versus corporatism is another set of concepts that have shaped the moral views concerning end-of-life care in the US. Corporatism is social-political system where the community is viewed as an organic body; hence, an emphasis is placed on common interests. Conversely, Individualism is a social-political system that views individuals as the basic units of society and places emphasis on promoting interest of individuals. Individualism is visible in Catholic traditions where people offer individual confession, receive the sacrament on an individual basis and judgment of sin on an individual basis. Consequently, the concept of individualism is more pronounced in American end-of-life practices than the concept of corporatism. Catholic medical ethics was more concerned with individual patients and doctors than with collective interests. Man was, and still is, viewed as an individual whose rights and interest were open to abuse by other members of the society. Therefore, the moral principles are focused on protecting these individual interests. The premise that end-of-life practices in the United States have been molded by the culture of individualism has been underlined by
Morrissey and Jennings. In their book, *Partners in Palliative Care; Enhancing Ethics in Care at the End-of-Life*, they argue that Americans are highly likely to make end-of-life decisions independent of family members influence. These authors continue to argue that American whites are more likely to exhibit an individualistic orientation than members of colored races when it comes to end-of-life decisions.

Pellegrino challenged the principle of patient autonomy citing that it does regard individuals as part of an intricate network of relationships. They argue that bioethical principles need to consider the implication of medical decisions on the interest of others. For instance, the decision to discontinue medical treatment of a parent may not affect the patient only, but will also affect a child who is still a minor. He emphasizes the importance of considering the interest of communities and families in decision-making at the end-of-life. However, Western bioethics rejects this view and considers family and community interests as considerations that patients should take into account but which should not be imposed on the patient. Jennings and Kahn argue that transferring all rights to determine the course of treatment to the patient can affect the quality of care adversely by undermining the morale of healthcare professions and the commitment of these professionals to their best for every patient. These bioethicists suggest that ethical principles should factor the interest of health caregivers in the decision-making as these caregivers develop medical and personal relationships with dying patients and have their own values. However, western bioethics suggests that the interests of physicians cannot outweigh the patient’s right of self-determination. Where there is a clash between the values of medical practitioners and the wishes of the patient, the wishes of the patient prevail.

Jennings and Kahn also argue that the need to protect the autonomy of patients should be balanced by the need to promote societal interest in the allocation of resources. At time,
providing care to patients at the end-of-life stage requires doctors to employ scarce resources such as ventilators, feeding technologies and others. Kelly, Magill and Ten Have advance the view that the societal interest of ensuring the efficient use of scarce healthcare resources should override the need to protect patients’ autonomy. This argument implies that the patient’s decision to continue with treatment at the end-of-life stage should be weighed against the benefits of the intervention. If there is convincing evidence that the intervention will not be of benefit to the patients then the need to make the medical resources available to other patients should outweigh the need to respect the desires of the patient to continue with the treatment. These ethicists argue that it is ethically permissible to deny resources to patients when there is overwhelming evidence that the resources are of little benefit to the patient and produce high-costs to the larger society.

Catholic theologians recognize the need for social considerations in the end-of-life decision-making process but consider this need secondary. Consequently, the end-of-life care system has emphasized the need to guard the rights of individuals such as autonomy and liberty. However, modern views of healthcare ethics recognize that the common good cannot be completely ignored. Modern bioethics, therefore, moves towards integrating corporatism and individualism. Modern healthcare ethics recognizes that too much emphasis on individualism can lead to decisions that neglect the common good while too much emphasis on corporatism can lead to unethical decisions. Therefore, modern moral views approach the concepts of individualism and corporatism as complementary rather than competing.

vii. Compassion

Compassion is another ethical value that influences American end-of-life practices. Compassion is more than sympathy and pity. It is the capacity to suffer and feel with the sick
person. It is ability to share the predicament, anxieties, fears, assaults and temptations of the patient and his family members. Compassion also goes beyond feeling and becomes a willingness to help and make sacrifices on behalf of the patient. Physicians have a moral obligation to identify with the suffering of terminally ill patients and their family members. The value of compassion is clearly stipulated in the AMA Principles of Medical Ethics. To medical practitioners, compassion is not a duty, but a virtue that they are expected to possess. This virtue enables physicians to extend the concepts of beneficence and nonmaleficence beyond the minimalistic interpretation. It encourages physicians to make sacrifices and risk their self-interest for the sake of the patient.

Compassion is a universal ethical value. Sharing in a person’s suffering does not mean that one approves the person experiencing the suffering or shares the reason that led to the suffering. For instance, showing compassion to a patient who contracted HIV/AIDS because she or he led an irresponsible life does not mean that one approves the lifestyle that led to the patient getting infected. Compassion is independent of the morality of the object. Compassion is also often proportional to the degree of suffering of the object. If the degree of suffering of the object is high, an ethical person will tend to show greater compassion to this object. Therefore, medical practitioners need to show compassion to all patients regardless of their background or the event that led to the illness. Compassion is the opposite of cruelty, where a person rejoices in the suffering of others.

Suffering is common among patients at the terminal stage of their illnesses. Apart from experiencing a great deal of physical pain, these patients feel abandoned and disconnected from other members of society. Other patients develop psychological problem because they feel that they have turned out to be a burden to others. Terminally ill patients also experience suffering
due to the distress brought about by the perceived or actual impending threat to the continued existence and integrity of the whole person. Many patients fear that the progression of their illness will make them lose their personal integrity. Other patients fear the loss of community and the perception of loss of self. This fear causes a great deal of anxiety and emotional suffering. The American end-of-life system recognizes the duty of healthcare practitioners to assist patients at the terminal stage of their lives overcome their suffering. The end-of-life system emphasizes the need to show compassion to patients. As already, passion not only entails sharing the patient’s experiences but also involves taking deliberate steps to alleviate the patient’s suffering. This action may entail withholding or withdrawing treatment so as to relieve the patient from his physical, emotional and psychological suffering. Another strategy for relieving the patient’s predicament is palliative sedation. Palliative sedation is a medical procedure that entails the continuous subcutaneous or intravenous administration of sedative drugs. Palliative sedation helps to lessen symptom distress of the patient’s illness.

viii. **Criterion of Death**

The recognition of cessation of brain activity as the criterion of death has also played a vital role in shaping ethical issues in end-of-life care. The concept of criterion-of-death is concerned with understanding when a person is considered dead. Although the concept of death criterion is mainly applied in the area of organ donation, it is also relevant to end-of-life care. The death criterion has a significant impact on decisions relating to withdrawing/withholding treatment. There is persistent disagreement concerning the criterion of death. In order to establish the criteria of death, one must first define death. Nair-Collins identified that from a medical perspective, death is defined as the irreversible cessation of the integrated functioning of the organism as a whole. This definition leads to the establishment of the brain death criterion since
medical practitioners were able to determine that the unresponsiveness of the brain leads to irreversible damage of the overall functioning of the body. Alternative arguments have been issued against the brain death criteria. Bernat, Culver, and Gert argue that a body with no brain function can be maintained on a ventilator and continue to function hence is still alive. However, this premise has been dismissed by modern scholars. Machado concluded that human life is about consciousness. This view implies that without consciousness, life loses most of its value.

In the past, death was associated with the cessation of respiratory function. The emergence of techniques such as Cardiopulmonary Resuscitation (CPR) and endotracheal intubation with mechanical ventilation proved that the cessation of respiration is not always the end of life. This concept was later replaced by the absence of the heartbeat but the emergence of procedures such as CPR showed that cardiac activities can also be restored; hence, the absence of the heartbeat cannot signify the end of life. The cessation of all cerebrocortical functions, a condition that was traditionally referred to as “coma dépassé”, remained as the only criterion that defines the end-of-life. This condition is irreversible and causes the loss of other bodily functions. Today, the cessation of brain function is used as the criterion for determining a person’s death. The growing acceptance of the brain death criteria in the American context has changed people’s understanding of death. There is increased awareness of the futility of existence in the absence of cognitive functions. This understanding of death supports the stance taken by the proponents of the quality of life perspectives. A patient that losses all cognitive functions is considered to have lost his life despite the fact that the functioning of the other body organs can be maintained using life support. The prolongation of life, in this case, does not
restore any meaningful existence. People who are in this state cannot exhibit any emotion or have any social relation.

The acceptance of the brain death criteria played a significant role in shaping ethical practices when it comes to caring for patients in persistent vegetative state. Patients in a persistent vegetative state do not meet the brain dead criteria as they possess some brain functions. However, patients in this state lose most of their cognitive functions such as reasoning irreversibly. These patients cannot hold any form of social interaction. Available treatment intervention cannot restore any meaningful activities in these patients. In this case, the need to preserve the patient life should be balanced with the need to uphold the dignity of the patient, promote the patient quality of life and make optimal use of healthcare resources.

C. Legal Views

The legal system that governs end-of-life care practices in the U.S. has been molded by various events. The cases of Karen Ann Quinlan, Nancy Cruzan, and Terry Schiavo are among these events. In 1975, Karen Ann Quinlan lost consciousness while at a party urging her friends to rush her to the emergency room. Quinlan lapsed into a coma before her parents could get to the hospital and was placed on an artificial support system. Quinlan’s parents asked the hospital to switch off the life support system after several months of waiting so as their daughter can die in peace. The hospital refused to implement the parents’ wishes stating that withdrawing life support was immoral. This contention led to a fierce legal battle between the hospital and Karen’s parents. In 1976, the New Jersey Supreme Court ruled that Quinlan had a constitutional right to privacy and that her father can exercise that right on her behalf. Quinlan’s father chose to disconnect the respirator. To most people’s surprise, Quinlan began to breathe on her own.
after the respirator was withdrawn and lived on for an additional ten years. The case paved way for the establishment of proactive steps for examining ethical issues that originate from the advancement of medicine. The most notable step was the passage of the country’s first living will law that sought to protect people’s rights regarding their medical treatment by the California Legislature. Other states followed suit.

The case of Nancy Cruzan took place almost a decade after Quinlan’s case. In 1983, Nancy Cruzan was involved in a road accident. Paramedics found no vital signs but were able to resuscitate her. She had gone into a deep coma by the time she arrived at the hospital. Medical practitioners gave the diagnosis that Cruzan was in a persistent vegetative state as she had suffered anoxia that caused her body functions to shut down. The hospital staff placed Cruzan on a respirator until she develops the capacity to breathe on her own. They also inserted a feeding tube because she could not eat or drink. After three years, Cruzan parents instructed the hospital to withdraw the feeding tube. The medical official refused stating that they needed a specific court order from the court of Missouri. This decision led to a court battle between Cruzan’s parents and the director of the Missouri Department of Health. The parents claimed that it was Cruzan’s wish not to continue her life unless she could live at least halfway normal. The Department of Health argued that the parents’ claims were unreliable since there was no written record that Cruzan did not wish to continue living. In 1990, the Missouri Supreme Court ruled in favor of the Department of Health. The parents appealed this decision at the United States’ Supreme Court, but the Supreme upheld the ruling by the Missouri Supreme Court. The ruling implied that it was acceptable for medical practitioners to require convincing evidence that the patient wishes the removal of life support. This court ruling popularized the concept of advance medical directives.
The Terry Schiavo case was the latest among the three landmark cases that shaped the legal framework that governed end-of-life practices in the United States. On 25\textsuperscript{th} February 1990, Terry Schiavo collapsed depriving her brain of oxygen for a lengthy period, a situation that left her in a persistent vegetative state.\textsuperscript{102} She could breathe without mechanical assistance, but she was incapable of emotion or thoughts. Terry Schiavo died 15 years later. An autopsy concluded that the damage she suffered on the brain was irreversible. The 15-year period when Schiavo was in a coma was marked by a fierce court battle between Schiavo’s husband and her parents. The husband wanted medical practitioners to detach the feeding tube stating that Schiavo never wanted to be kept alive that way. The parents insisted that medical practitioners keep the tube in place saying that this is what their daughter wanted. The Florida court backed the husband’s argument as a matter of law, but local and federal politicians sided with the parents’ position. After a protracted legal battle, the decision of Florida State Court prevailed leading to the detachment of the feeding tube, in 2005.\textsuperscript{103} Terry Schiavo’s case not only shaped the legal landscape relating to end-of-life practices, but also shaped the social and cultural landscape. Due to the publicity that the case generated, many Americans prepared living wills and comparable directives. Schiavo’s case highlighted the importance of having an objective means of determining the patient wishes in the event of incapacitation and where the opinion of family members is sharply divided.

These court cases demonstrate that forgoing treatment is the most contentious legal issue when it comes to end-of-life practices. The American legal system has come to a general agreement regarding this issue. This agreement is founded on five main tenets; distinction between ordinary and extraordinary means; distinction between killing and letting patients to die;
right to privacy, autonomy and liberty; permitting the use of surrogate, and allowing the use of advance directives.

i. **Ordinary and extraordinary means**

The first pillar of consensus regarding the issue of forgoing treatment is the distinction between ordinary and extraordinary means of sustaining life. This pillar recognizes that not all treatments that prolong life are beneficial to the patients. The pillar calls for the distinction between ordinary and extraordinary means of sustaining life. This pillar suggests that some medical treatment options are not obligatory; hence, they can be foregone. The pillar refers to these treatment options as extraordinary treatment. Conversely, this pillar notes that there are treatment options that offer significant benefits to patients; hence, are obligatory. The pillar refers to these treatment options as ordinary means. This distinction originates from the Catholic doctrine. In 1980, the Vatican issued the declaration that medical practitioners can make the correct judgment regarding the means of treatment by comparing the type of treatment, the level of difficulty and danger, the expenses, and the practicality of applying the treatment with the outcomes that they expect.\textsuperscript{104} This declaration proposes that it is right for medical practitioners to discontinue medical procedures that are burdensome, extraordinary, dangerous or disproportionate to the expected outcomes.

The distinction between ordinary and extraordinary treatment is also visible in the American legal system. In the case of Superior Court versus Barber, the California Court ruled that the physician failure to continue treatment of a patient in vegetative state at the request of the patient family did not amount of unlawful failure to perform a legal duty; hence, the act is not punishable by law. In the case, two physicians were arraigned in court facing charges of murder
and conspiracy after they discontinued treatment of a patient in a vegetative state at the request of the patient’s family. The ruling proposed that physicians may be exempted from the duty of care where it is proven beyond reasonable doubt that the treatment was burdensome and had no meaningful benefit to the patient. Therefore, practitioners cannot be held liable on the basis of duty to care when they fail to administer treatment that has been proven to be futile.

ii. Killing and Allowing to Die

The second pillar of consensus regarding the issue of forgoing treatment is the recognition of the legal difference between killing and letting as patient to die. This distinction is also founded in Catholic traditions. This pillar justifies the act of allowing patients to die by differentiating it from killing. The pillar also condemns actions that cause death stating that such actions are wrong and illegal. In the past, there was a contentious debate regarding the morality of actively killing terminally ill patients through acts such as administration of lethal medications. People often use various terms to refer to such actions including euthanasia, assisted suicide or physician aid in dying. A section of scholars argues that euthanasia is morally right if it relieves the patient’s suffering and allows the patient to have a dignified death. However, the third pillar rejects this argument and maintains a distinction between active killing and allowing patients to die. This distinction is also evident in the American legal system.

Five actions emerge in the discussion of the distinction between killing and letting a patient die. These actions include withholding life-sustaining treatment, withdrawing life-sustaining treatment, pain relief that hastens death, physician-assisted suicide, and euthanasia. Withholding life-sustaining treatment entails not using certain medical treatment that would prolong life. This action does not amount to the killing of a person but allowing a person to die.
It is right to withhold life-sustaining treatment when the treatment is burdensome and will not improve the quality of life of the patient. Withdrawing life-sustaining treatment entails stopping the use of a treatment option that had already begun. It may entail detaching a feeding tube or turning off the ventilator. In the American legal system, withdrawing life-sustaining treatment is equivalent to withholding life-sustaining treatment. Withdrawing life-sustaining treatment is permissible where the treatment is burdensome and will not improve the quality of life of the patient. The lack of distinction between withholding and withdrawing life-sustaining treatment is critical for various reasons. First, it prevents the use of unwanted or useless treatment; hence, ensure optimal utilization of scarce resources. It also eliminates the dangers of under-treatment. Patients and their families will not be afraid of commencing treatment procedures when they know that they have the option of withdrawing.

In some instances, medical practitioners have to administer drugs that aim at relieving pain but that also hastens death. These drugs are not intended to cause death but act as co-cause of death. For instance, doctors are often forced to increase the dose that patients need to eliminate pain when such patients develop tolerance to the pain relief drugs. Increasing the dosage suppresses the respiration process contributing to the death of the patient. This kind of medication is not considered legally wrong in the United States. The law permits medical practitioners to use such medications to relieve the patient’s suffering.

Physician-assisted suicide is an act that entails providing the patients with means for ending own life. The patient initiates the suicide act and the physician only plays the assisting role. It is legally wrong for physicians or any other person to assist patients to commit suicide in 45 states. Euthanasia entails taking action that directly leads to the death of the patient. Active euthanasia is illegal in 45 states. Several landmark cases have shaped American laws regarding
physician-assisted suicide. *Vacco versus Quill* is one of these landmark cases. In this case, a number of New York physicians filed a suit against the New York Attorney General for making it a crime for physicians to administer lethal medication or intentionally terminate the life of a patient even with the consent of a mentally competent patient. The physician argued that the law violated patients’ liberty protected by the Constitution. The attorney general’s office advanced the argument that the statute violated equal protection, and fourteenth amendment clauses not that patients did enjoy the right to permit physicians to terminate their lives. The district court made a verdict that favored the opinion of the attorney general, but the physicians appealed this decision. The New York Court of Appeals overturned the District Court’s decision stating that the New York law did not treat all competent patients equally. The New York Court of Appeals articulated that it is discriminatory to allow a patient to remove life support system and deny another patient who is in a similar condition the right to have his doctor administer a lethal drug. The case moved to the Supreme Court of the United States where it decided (9-0) that the New York laws that prohibit physician-assisted suicide was constitutional as they fall within legitimate state interests of preserving life, protecting the integrity of the medical profession, avoiding third party involvement and undue influence over patients’ decisions to live or die, and avoiding future abuses.

Physician-Assisted Suicide is clearly a highly controversial issue in medical ethics. Some ethicists argue that this practice should not be tolerated because it is possible to provide the dying or terminally ill and suffering patient with palliative care and, further, that many individuals requesting such assistance are suffering as well from depression and are not mentally competent or able to make such a request. Others contend that even a depressed patient is, more often than not, entitled to autonomy and to make decisions on his or her behalf and,
consequently, that physicians should be permitted to honor such requests in most if not all cases. Most physicians believe that in cases when a terminally ill patient is diagnosed with clinical depression, a request for PAS should not be honored unless and until a competent set of clinicians have determined that the patient is sufficiently in control of his or her mental faculties to understand the meaning of the request and its consequences.

Offering a person counseling for depression before approving PAS is, however, an important procedure. This kind of assessment will help doctors determine if the patient is sufficiently knowledgeable regarding his or her condition and prognosis to make a rational, informed decision. It will help to ensure that the request is not capricious or ill-founded. Depression related to a terminal condition does not seem to be a “separate condition” per se, particularly if prior to the advent of the condition, the patient was not suffering from such a mental problem. Is it simple to diagnose depression in terminally ill patients?” Certainly, the terminally ill patient should be assessed by psychiatrists and physicians before any final decision is made regarding a request for assistance in dying. Medical ethics committees should be proactive in establishing a screening process in such instances, and physicians must always work within the limits imposed upon them by the law.

Washington v. Glucksberg is another landmark case that shaped the legal framework that governs the issue of physician-assisted suicide. In this case, Glucksberg and other parties challenged the State of Washington’s decision to ban assisted suicide using the Natural Death Act of 1979. Glucksberg and company argued that suicide and assisted suicide was a liberty that is protected by the Due Process Clause of the 14th Amendment to the American Constitution. The district court made a verdict that favored Glucksberg and company, but the U.S. Court of Appeals reversed the decision. The U.S. Court of Appeals held another hearing that led to a reversal of its earlier decision and affirmation of the decision by the District Court. The case
moved to the U.S. Supreme Court, which ruled that the Due Process Clause does not protect the right to assisted suicide.

The two cases determined that physician-assisted suicide was not protected by the Constitution but did not outlaw this practice. State governments were left with a free hand to determine whether to legalize or outlaw physician-assisted suicide. Forty-five states have since enacted legislations that prohibit assisted suicide while five states have laws that permit this practice. The State of Oregon is among the few American states that have legalized physician-assisted suicide (PAS). Plaisted criticized Oregon’s PAS legislation stating that it undermined the dignity of patients at the terminal stage of their illness. This legislation gives patients at the end-of-life stage the right to receive physicians’ assistance in terminating their lives but does not give other people the same right. Plaisted argues that the legislation implies that the lives of patients at the terminal stage of their illness are not valuable enough to warrant state protection; hence, the legislation undermines the dignity of these patients. The PAS legislation suggests that patients at the terminal stage of their illness have no life to protect; hence, the state does not have to exercise its legitimate interest in their lives.

A discussion of Oregon’s Death with Dignity Act, also known as Measure 16, became law via a voter referendum in 1997. Oregonians approved this measure by a slim margin of 51 to 49 percent. The measure had been proposed initially in 1994 and approved by the electorate but opponents of the law filed suit before the U.S. District Court in the case of Lee v. State of Oregon. The Court temporarily halted the implementation of the law and inevitably the case made its way to the U.S. Supreme Court. Ultimately, the Oregon statute has been successfully defended against multiple legal and political attacks including Measure 51, a legislative effort to nullify or overturn the law and legal battles in many different courts.
The Oregon statutes on physician assisted suicide are relatively straightforward and are rigorously maintained. They require that any individual seeking to terminate his or her life be a minimum of 18 years old or more and to have been diagnosed as terminally ill with less than six months to live. Further, the individual must be identified by competent physicians as capable of making such a request as it is understood in a legal sense with regard to mental competence. Counseling must be provided to an individual requesting such services by licensed caregivers before such a request will be granted.113

Thus, the law has multiple safeguards that are designed to prevent the abuse of the right to death with dignity and to oversee activities of physicians who perform such services for patients. The detailed description of what goes into a viable request for life-ending medication is delineated in Oregon law and it is essential that any individual seeking such assistance be carefully screened to ensure that he or she is fully competent to make such a request.

Kitchen has pointed out that Oregon’s law bans physician assisted suicide for mentally disabled individuals and for any individual who is seen by competent evaluators as unable to make such a decision.114 It is clear that one of the goals of the legislation is to ensure that physicians and other healthcare givers will not be allowed to decide autonomously that a patient should be euthanized. That said, opponents of Oregon’s law have often expressed concern that by its very existence, it serves to create a slippery slope which government agencies or other actors could use to employ without the consent of patients or their guardians and caretakers. There are concerns that the law could be perverted to violate the civil rights of people with disabilities or even to make it possible to engage in the kind of “genetic engineering” that took place in Nazi Germany where disabled and mentally ill individuals were euthanized without their consent or the consent of their family members.
There are also concerns expressed by religious groups that the practices permitted under Oregon’s law represent a violation of the moral and ethical codes of most world religions. These are legitimate concerns. The inclusion of safeguards may not necessarily satisfy those who make such complaints. Nevertheless, it should be noted that the Oregon law requires that the individual making the request do so verbally on two occasions separated by 15 days and then submit a written request for termination of their life to their attending physician that has been witnessed by two individuals who are neither primary caregivers nor members of the patient’s family.

The patient must be able to rescind both verbal and written requests at any time. The patient must be able to administer the prescription by himself or herself. The doctor must be licensed in the state of Oregon and must have rendered a diagnosis that the patient has six or fewer months to live due to a terminal condition. The law further requires that a consulting physician must verify the diagnosis as well as the mental competence of the patient making such a request. Finally, the attending physician is obligated under the law to inform the patient of available alternatives including palliative care, hospice, and pain management.

It would appear on balance that Oregon’s law has addressed many of the most significant issues related to a patient’s request to put an end to his or her life due to a diagnosis of a terminal illness. Nevertheless, the law remains controversial and is likely to do so. Not everyone in the medical field sees this law as desirable.

**iii. Patient Autonomy, Right to Privacy and Liberty**

The United States legal system combines the three pillars of consensus with the legal concepts of the right to autonomy, right to privacy and liberty to decide for oneself. The principle
of patient autonomy is founded on the belief that human beings are rational creatures that are capable of making rational decisions. The law that grants patients autonomy is founded on various sources including the American Constitution, which guarantees every citizen his or her individual liberty and right to privacy. It is also founded on common law liberty, which grants people the right to refuse unwanted touching. The practical connotation of this rule is that it gives patients the right to accept or refuse treatment. In 1990, a United States Supreme Court ruled that patients who are capable of making rational decisions have the right to reject treatment. The American legal system upholds the patient’s right to refuse treatment with distinguishing between extraordinary and ordinary treatment. This legal provision implies that a patient can reject a treatment that is ordinary in nature such as an appendicitis surgery as long as the patients have the capacity to refuse treatment for themselves. The right to privacy and autonomy always prevail in such cases. The right to refuse treatment is exempted in two occasions; (1) where the case involves a pregnant woman, and (2) in the case of parents, usually mothers of small children. However, the law permits medical practitioners to convince the patients to accept a given treatment if the treatment has medical benefits.

The principle of respect for patient autonomy recognizes that the ultimate source of decision making authority resides with the patient. Any patient who is capable of making decision has the right to determine what should happen to his body. Consequently, she or he has the right to refuse any form of therapy, whether ordinary or extraordinary. However, the right to reject treatment is not unlimited. The law recognizes four compelling state interests that can be used to deny patients the right to refuse treatment. These four state interests include the preservation of life, the maintenance of the ethical integrity of the medical profession, the protection of innocent third parties, and the prevention of suicide. While the state has a duty to
respect the autonomy of individuals, it must ensure that the recognition of this right is not used to coerce innocent third parties into refusing treatment. It also has an obligation of protecting the integrity of the medical profession and preserving the sanctity of life. The state interest declines and individual autonomy increases the level of invasiveness of the intervention increases. For instance, a patient may have greater autonomy to refuse a surgical operation than to refuse the administration of oral antibiotics because the former intervention is more invasive than the later.

**Conclusion**

There are, as this chapter demonstrates, many contentious issues still unresolved within the American health care system related to end-of-life care. Those who support legalization of physician-assisted suicide or euthanasia argue that the right to choose death over a painful, lingering final illness or a condition for which no cure exists is a basic human right. Healthcare givers have a duty to ameliorate pain and suffering, it is argued, and there are cases in which this may require agreeing to allow a competent adult patient to choose death over a prolonged period of suffering. Supporters do caution that the individual requesting such assistance must be mentally and psychologically competent to make such a decision. The responsibility of the physician is perceived as focused on ending rather than prolonging suffering.

Opponents of this practice argue that the decision to terminate one’s life is often influenced by temporary mental anguish or despair and that such a decision must be carefully considered in light of all the circumstances of the patient. The Hippocratic Oath requires that first, physicians must do no harm; aiding the suicidal patient results in harm that cannot be remedied. Many physicians argue that palliative medical care can reduce the pain and suffering of the individual who is terminally ill or afflicted with a condition that can be improved upon.
The United States’ end-of-life care system has come a long way. Bioethics scholars have managed to reconcile the different ethical views associated with this system and introduced consistent standards that guide decision-making processes. This chapter has analyzed the United States’ end-of-life care practices with a specific focus on legal and ethical principles that support decision-making processes. This discussion paves the way for the comparative analysis where the US system is compared to the Saudi Arabian system. Chapter Three will examine the Saudi Arabian end-of-life practices.
Chapter Three
The Saudi Arabian End of Life Care Practices

Introduction

Throughout history, “monotheistic religions and medicine have caused numerous acrimonious debates especially in crucial moments of life and death.” In the Kingdom of Saudi Arabia, as is the case in most predominantly Muslim countries, all aspects of life are governed by Shari’a, itself derived from multiple sources such as the Qur’an, the Hadith (the sayings and commentary of the Prophet Muhammad), and fatwas or the rulings of Islamic scholars. Religion is therefore the single most significant element in defining Saudi Arabian medical practice including many different aspects of health care decisionmaking, including decisions regarding the end of life.

Indeed, Eleanor Doumato pointed out that “a healthy majority of Saudi citizens agree with the social agenda of the ulema” and the country is home to a state bureaucracy which is derived from a “literal reading of the Koran and Sunna.” This chapter of the study addresses three critical issues relevant to end of life care practices in Saudi Arabia: the principles and rules for ethical and legal decisions, specific end of life decisions in Islam, and the health care system in Saudi Arabia. Drawing upon the literature, the chapter demonstrates that Islamic bioethics is normative in many different instances including the necessity of preventing harm while supporting life.

The chapter will describe the principles and rules for ethical-legal decision making inherent in Islam, and then examine Saudi Arabia end of life practices and issues. It will offer an overview of the Saudi Arabia health care system as an example of an Islamic health care system that is modeled upon the ethical and legal principles espoused by Islam and shari’a law.
**A. Principles and Rules for Ethical-Legal Decisions**

The Islamic tradition emerged on the Arabian Peninsula between 570 and 632 A.D. with the birth of Muhammad, the Prophet to whom Islam was revealed. From the beginning, “Islam saw itself as a community created by God in fulfillment of God’s promise to send a prophet to every people. Muslims believed that the message from God to the Arabs would be the last and the most complete.”122 While distinct from both Judaism and Christianity, Islam was nevertheless intricately woven into the cultural and ideological fabrics of those earlier monotheistic religions. Islam grew rapidly, putting down deep roots throughout the Middle East and North Africa (MENA) region and spreading into East Asia and parts of Europe as well.

Religious leadership was shaped according to sect: in Sunnism, the scholarly class known as the ulama created what has become Sunni Islam while in Shiism, Imams developed religious laws, theology, and imamate philosophy.123 The Islam of the court and of the developing Muslim intellectual class embedded in Sunni Islam adopted the medical systems and heritage of Greece, India, and Persia and built upon those traditions even though in rural areas where access to such training was limited Arab folk traditions blended with popular conceptions that were attributed to the Prophet Muhammad. Waugh states that “both systems – intellectual and folk – were eventually absorbed into basic Islamic ideology with two ends.”124

On the one hand, physicians assumed moral responsibilities for health shaped in large measure by pious Muslim commitment to notions of the value and meaning of life as well as an understanding of the prevention of harm as a key ethical and normative philosophy. Conversely, the legacy of Muhammad established a perception of good health as the right of all, opening doors for people seeking assistance in achieving and maintaining good health. Sufism introduced an element of mysticism into health care and health beliefs but it can be argued that
from the very beginning Islam has emphasized the belief that health is a gift or blessing from God as stated in Qur’an 40: 64, “he (Allah) formed you and formed you beautifully.” As Waugh points out, ‘through human creation, God set in place his moral domain, making everything in the heavens and on earth subject to humans (31: 20; 16: 14), and in trusting to humans from pre- eternity (33: 72) the well-being of all beings and things on earth (2: 29).”  

Islamic bioethics is an extension of Shari’a, which is itself based on two foundations: the Qur'an (the holy book of all Muslims, whose basic impulse is to release the greatest amount possible of the creative moral impulse and is itself a healing and a mercy to those who believe and the Sunna (the aspects of Islamic law based on the Prophet Muhammad's words or acts). Development of Shari’a in the Sunni branch of Islam over the ages has also required *ijmaa* (consensus) and *qiyas* (analogy), resulting in four major Sunni schools of jurisprudence. Where appropriate, consideration is also given to *maslaha* (public interest) and *urf* (local customary precedent). The Shia branch of Islam has in some cases developed its own interpretations, methodology and authority systems, but on the whole its bioethical rulings do not differ fundamentally from the Sunni positions. In the absence of an organized “church” and ordained “clergy” in Islam, the determination of valid religious practice, and hence the resolution of bioethical issues, is left to qualified scholars of religious law, who are called upon to provide rulings on whether a proposed action is forbidden, discouraged, neutral, recommended or obligatory. 

The principles and rules for contemporary responses to ethical dilemmas from a Muslim perspective thereby derive from the revealed word of Allah as found in the Qur’an, the Hadith, and the legal doctrines and rules embedded in *fatwas* described as revealing “the insights of a jurist who has been able to connect cases to an appropriate set of linguistic and rational
principles and rules that provide keys to a valid conclusion for a case under consideration.**127**

The Oath of the Muslim Doctor includes an undertaking that calls for protection of human life in all stages and under all circumstances, doing one's utmost to rescue it from death, malady, pain and anxiety and being an instrument of God's mercy, by extending medical care to near and far, virtuous and sinner and friend and enemy.

End of life issues are widely acknowledged as religiously, politically, culturally, and emotionally charged decisions. Islam teaches that life is a gift from God, that God wants his creatures to enjoy life and to experience well-being, and that life is sacred because God is its origin and its destiny. Death “does not happen except by God’s permission…. Nevertheless, there is recognition of the fact that diseases and trauma cause death. In Islam, health care providers must do everything possible to prevent premature death.”**128** That being said, however, Islamic law and ethics do not call for unnecessary prolongation of life when it is clear that life is ending or that there are inadequate resources to continue the life of the individual in a manner that would be essentially beneficial.

In discussing Islamic views on the critical issue of end of life decisionmaking and medical caregiving, it is important to note that in Islam, “belief in resurrection illuminates that the spirit in the other world frees and purifies from pains and sorrow of the nature and material world. The Holy Qur’an states: ‘the angel of death, who is given charge of you, shall cause you to die, then to your Lord you will be returned (32: 11).”**129** The sanctity of human life is ordained in the Qur’an wherein Sura 6: 151 states “do not take life which God has made sacred except in the course of justice.” Life is therefore sacred to the Muslim who also believes that death occurs only with the permission of God and that the saving of a life is one of the highest merits in Islam. Consequently, “health care providers must do everything possible to prevent premature death.
Muslim jurists of different schools ruled that once invasive treatment has been intensified to save the life of a patient, life-saving equipment can not be turned off unless the physicians are certain about the inevitability of death.”

The primary obligation of the Muslim physician, therefore, is to provide care and to alleviate pain and suffering. However, the Qur’an points out that pain functions as a kind of test or trial which serves to confirm a believer’s spiritual station. Pain functions “as an instrument in revealing God’s purpose for humanity and in reminding us that ultimately we belong, and will return to, God.”

The Qur’an (21: 35) states that: “every soul shall have a taste of death: and we test you by evil and by good by way of trial, to Us must you return.” Pain purifies but also educates and some Muslim scholars have concluded that despite this, patients in pain from terminal illnesses may legitimately receive analgesic medicine until the time of death. Muslim jurists derive much of the decisionmaking from the Islamic ethical rule which states that “no harm shall be inflicted or reciprocated in Islam” – a rule which “allows for important distinctions and rules about life sustaining treatments in terminally ill patients; the distinctions on which ethical decisions are made include the difference between killing (active euthanasia) and letting die (passive euthanasia).”

The Shari’a is the religious law of divine origin revealed and structured according to the definitions of jurists from the first centuries of the faith forward. According to Dariusch Atighetchi, “in other words, the Shari’a is far more extensive in the sphere of the private, social, political, and religious life of the believer” than Western law. For Muslim law, each human act can be categorized as either compulsory, recommended, free, reprehensible, or unadvised or forbidden. Though flexible and adaptable, Shari’a holds true to the four roots of the law or usul
by analogy/qiyas.

Essentially a salvific religion, Islam requires its members to assist the ill day and night and identifies the role of the doctor as recalling the divine role stated in one of the first Arabic texts on medical ethics “in which medicine is defined as an art given by God that imitates His curative role.” The Islamic Code of Medical Ethics of 1981 calls the physician a “soldier for life” while stating that the physician is “an instrument that God uses to relieve human suffering and, lastly, medicine is sacred as it brings one closer to the faith by means of contemplation of what has been created.”

It is, of course, important to note that Islamic bioethical principles impacting upon the practice of medicine in general and end of life care decisions in particular has been impacted by a number of external factors. For example, new biological technologies, medical procedures, diagnostic tools and techniques, and other shifts in what medical caregivers can provide are directly challenging many traditional medical practices in the Muslim world as well as the Christian or Jewish communities. Further, the attempt at modernization “instigated by bioethics represents an opportunity to update certain rules and values of the past.”

There is a burgeoning interest in the field of Islamic bioethics within public and professional circles. Shari’a, according to Al Padela, remains normative throughout the Western world but with the migration of Muslims to social settings that are inherently non-Islamic or multicultural and therefore diverse, Muslim physicians are being challenged to adopt or accept medical practices that any not necessarily be in accord with their own faith. The issue is of course less significant in the context of Islamic countries such as Saudi Arabia.
Islam has retained “notions of death and dying that cannot be found in any of its sacred sources.” For example, many Muslims believe that it is particularly meritorious to die while on pilgrimage to Mecca while others contend that dying during the Ramadan fast is significant and provides the deceased with benefits that otherwise might not occur. With this in mind, Sachedina notes that the Islamic Juridical Council (IJC), an organization of the Islamic Conference (OIC), has brought together jurists belonging to all schools of legal thought in Islam that work to formulate responses to a variety of bioethical questions and issues. This pair of organizations work to achieve better understanding of revealed law in the Qur’an. The fundamental questions that sit at the heart of Islamic bioethics center on the origins of life, the role of compassion and relief of suffering, and the inevitability of death.

i. Life Is a Gift from God

In Islam, life is viewed as sacred because it originates as a gift from Allah. Consequently, Islam emphasizes the importance of saving and respecting life as a means of demonstrating one’s respect for Allah and acceptance of the great gift that mankind has been given. Good health is further seen as a blessing from God which suggests that illness is conceived of as an evil that should be eliminated or an affliction that is to be cured. The purpose of medicine and medical practice, therefore, is “to search for a cure through the application of human knowledge and scientific endeavor and to provide the necessary care to those afflicted with diseases.”

Bagbi notes that the Qur’an clearly stipulates that an individual who has saved the life of another human being has in essence saved the life of all of mankind; this teaching is normative in Islamic medical practice and for centuries has shaped the ways in which Muslim physicians have practiced their profession. Because this is the case physicians are also encouraged to consider
the use of any and all treatments or interventions that have a high probability of saving the life of a patient.

Atinghetchi suggests that Muslims are firm believers in predestination, attributing pain and pleasure alike to God’s will and viewing suffering as a mechanism which allows the individual to atone for sin. The result is that Muslims accept the necessity of perhaps enduring serious, painful, and life threatening injuries and illnesses with Islamic teaching holding those men and women able to endure physical pain in high esteem. As the Qur’an states, Muslims must give glad tidings to those who, when afflicted with calamity, endure and persevere with patience, dignity, and acceptance.\(^{143}\)

The general thrust of Muslim belief is that the community must sustain an individual “until it is obvious that the believer must face God. Prolonging that moment will serve no religious purpose.”\(^{144}\) Nevertheless, Muslims believe that God formed mankind beautifully, creating each human as a unique package or individual in which a spiritual essence is embedded in the physical body. Throughout human creation, Muslims believe that “God set in place his moral domain.”\(^{145}\)

In various texts found in the Hadiths, health is presented as a blessing from God and other texts stress “that the life God gives one is to be enjoyed, so long as one lives within moderation. Thus, personal well-being is once again elaborated in terms of a well-balanced, upright stance before God.”\(^{146}\) It is, therefore, essential to recognize that Muslims value life and Muslim physicians perceive their role as one requiring them to be proactive in assisting other Muslims in achieving the blessings that God surely conferred upon mankind.

With life originating from Allah, Muslims are required to live the kind of life that will maximize health and well-being and which will give them multiple opportunities to demonstrate
their submission to God’s will and their simultaneous appreciation for the blessings they have been given. It is important to understand that “piety of the Qur’an, love for the Prophet, and pious attendance to God’s everyday requirements as found in the law” shape Muslim life.147

The life of a human being in Islam is regarded as sacred. A doctrine to which every Muslims submits is that “no soul dies except by Allah’s permission.”148 Physicians in Islamic countries often face questions regarding end of life care and the withholding of life prolonging treatment that will not improve the quality of life but merely sustain it for a period of time. The presidency of the Administration of Islamic Research, located in Riyadh, Saudi Arabia, issued Fatwa No. 12086 in 1988, stating that “if three knowledgeable and trustworthy physicians agreed that the patient’s condition is hopeless, life supporting machines can be withheld or withdrawn. The family members’ opinion is not included in decisionmaking as they are unqualified to make such decisions.”149

In essence, this particular Fatwa affirms the Quranic emphasis on the sanctity of human life while acknowledging that medical professionals are in an ideal position to determine when and even if it is appropriate to acknowledge that the God given life of an individual is rapidly coming to an end and, consequently, that it would be inappropriate to use scarce resources to artificially and indefinitely prolong that life solely in order to allow the Muslim to experience the mandatory suffering that accompanies all human life.

Takrouni and Halwani also point out that Islamic law or Shari’a acknowledges that individual autonomy must be respected.150 However, Islam returns again and again to the Qur’an in acknowledging that a proper relationship with God and attitudes of gratitude are necessary for well-being because it is only God who “can assist humans in getting beyond their self-centeredness.”151 An upright stance before God is required of Muslims who must accept the
reality of death as the natural end of life and who must further expect that life will include periods of suffering.

**ii. Compassion and the Relief of Suffering**

Fundamental to the human condition as described in the Qur’an is an understanding of the fact that suffering and pain are likely to occur in the life of every individual. Human beings are prone to selfishness and often have a somewhat limited perspective on their responsibilities not only to themselves but to others. Health is a blessing from God and in the Hadith there are “specific physical and spiritual guidelines for cleaning oneself before prayer, practices believed to help maintain a well-rounded society. In general, the Hadith stress that the life that God gives is one to enjoy as long as one lives within moderation.”

However, Islam also recognizes that relieving human suffering is a virtuous act. Islam does not exalt suffering per se but it acknowledges that it can be linked to atonement for sin and redemption. Shari’a is typically regarded as a vehicle which provides benefits to Muslims and not as a means of punishing Muslims. However, it is equally true that Shari’a acknowledges that suffering is inevitable because of human frailty. What this means is that physicians are permitted to give patients experiencing pain those pharmaceutical preparations that are traditionally prohibited by Islamic law with respect to their use as non-medical or recreational drugs. This is certainly an important consideration because many individuals as they approach death find themselves in extreme pain and call upon their physicians to provide them with relief from pain.

One of the key rules that govern Islamic bioethics was described by Athar, who commented that Islam recognizes that necessity can and should override prohibition. This particular ruling overrides the prohibition against the use of substances known as *haram* – opioids and other pharmaceuticals that have the capacity to alleviate pain and thereby provide...
meaningful relief to the suffering individual. The rule of necessity overriding prohibition also comes into play because Islamic values emphasize the importance of exhibiting sensitivity towards the ill person as well as assisting those who ill in obtaining care. To be a Muslim means that one must exhibit charity toward others – which is not limited merely to tithing a portion of one’s income or wealth, but which includes providing all kinds of assistance to individuals who are suffering.

The terminally individual is likely to be in need of such compassion. In critical care medicine and intensive care units (ICUs) throughout Saudi Arabia, physicians and other medical caregivers are challenged to respond compassionately to the suffering individual and to offer assistance that can be instrumental with respect to the relief of pain. Stewardship of the body and pain are addressed in the Qur’an which points out that “pain is a form of test or trial, to confirm a believer’s spiritual station.”

The Qur’an (2: 153-157) states that:  O you who believe, seek assistance through patience and prayer; surely Allah is with the patient… surely we will try you with something of fear and hunger, and diminution of goods and lives and fruits; yet give thou good tidings until the patient, who, when they are visited by an affliction, say, ‘Surely we belong to God, and to Him we return.’” Pain therefore is seen by Muslims as an instrument revealing God’s purpose for humanity while reminding believes that ultimately we belong and will return to God. Pain is therefore not to be construed of as evil but as a mechanism for responding to God’s trials and demonstrating one’s belief in God’s power “to heal and restore health (which) is the major source of human desperation.”

Muslims mount an active response to pain and suffering because this is regarded as a righteous act. The Qur’an (11: 114) states that “surely the good deeds will drive away the evil
deeds.” Today, Muslim physicians as well as most Muslims embrace the new technologies and medications that alleviate pain particularly as the end of life approaches.

**iii. The Inevitability of Death**

A number of verses in the Qur’an serve to underscore the inevitability of death. Some of these are:

*Al-Baqara (The Cow)*

- 2:94 (Y. Ali) Say: “If the last Home, with Allah, be for you specially, and not for anyone else, then seek ye for death, if ye are sincere.”

*Al-Imran (The Family of Imran)*

- 3:185 (Y. Ali) Every soul shall have a taste of death: And only on the Day of Judgment shall you be paid your full recompense. Only he who is saved far from the Fire and admitted to the Garden will have attained the object (of Life): For the life of this world is but goods and chattels of deception.

*An-Nisa (The Women)*

- 4:18 (Y. Ali) Of no effect is the repentance of those who continue to do evil, until death faces one of them, and he says, “Now have I repented indeed;” nor of those who die rejecting Faith: for them have We prepared a punishment most grievous.

- 4:78 (Y. Ali) “Wherever ye are, death will find you out, even if ye are in towers built up strong and high!” If some good befalls them, they say, “This is from Allah.; but if evil, they say, “This is from thee” (O Prophet). Say: “All things are from Allah.” But what hath come to these people, that they fail to understand a single fact?

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*Al-An’am (The Cattle)*
• 6:61 (Y. Ali) He is the irresistible, (watching) from above over His worshippers, and He sets guardians over you. At length, when death approaches one of you, Our angels take his soul, and they never fail in their duty.

Al-An’am (The Cattle)

• 6:162 (Y. Ali) Say: “Truly, my prayer and my service of sacrifice, my life and my death, are (all) for Allah, the Cherisher of the Worlds:

Al-A’raf (The Heights)

• 7:158 (Y. Ali) day: “O men! I am sent unto you all, as the Messenger of Allah, to Whom belongeth the dominion of the heavens and the earth: there is no god but He: it is He That giveth both life and death. So believe in Allah and His Messenger, the Unlettered Prophet, who believeth in Allah and His words: follow him that (so) ye may be guided.”

Al-Anbiya (The Prophets)

• 21:35 (Y. Ali) Every soul shall have a taste of death: and We test you by evil and by good by way of trial. to Us must ye return.

Al-Mu’minun (The Believers)

• 23:80 (Y. Ali) It is He Who gives life and death, and to Him (is due) the alternation of Night and Day: will ye not then understand?

Al-‘Ankabut (The Spider)

• 29:57 (Y. Ali) Every soul shall have a taste of death in the end to Us shall ye be brought back.

Ar-Rum (The Romans)

• 30:50 (Y. Ali) Then contemplate (O man!) the memorials of Allah’s Mercy!- how He gives life to the earth after its death: verily the same will give life to the men who are dead: for He has power over all things.

This selection of verses from the Holy Qur’an serves to demonstrate that: 1) death is inevitable; 2) death is a natural end of life; 3) the time of death is firmly in the purview of Allah who oversees all activities occurring in the world He has created; 4) the way that an individual dies is of significance; and 5) death occurs only with the consent of Allah and independent of medical judgments which are based on human rather than divine understanding. 

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The inevitability of death is a reality for all humans. Waugh states that “the Qur’an is forthright about death as a major passage to another life. In Islam, it is not quite true to say that death is the cessation of life, but rather that the life one receives at birth is preparatory for the life after death.”\textsuperscript{159} Further, a Muslim traditionally does not die alone, isolated or segregated from relatives or friends. While the faith does not accept any form of mediation between God and man, the emphasis on community means that a support system is supposed to surround the dying individual at the decisive moment. In both the Qur’an and in popular belief, Muslims pray earnestly for what could be called an easy death. This means that it is vital to ensure that the individual approaching death is prepared to meet God by praying the required confession of faith: “there is no God but God, and Muhammad is His messenger.”\textsuperscript{160}

The view that death is inevitable ensures, said Pagbi, that Muslim physicians are well within ethical boundaries when they elect to withdraw or withhold life sustaining treatments or mechanisms that serve merely to prolong the life of a terminally ill patient.\textsuperscript{161} Practitioners are expected to do everything that is possible or reasonable to prevent disease and stave off death from disease and also to assist the dying individual in retaining consciousness until he or she has made the confession of faith and sought forgiveness for any wrongs that he or she may have committed. From a religious point of view, “mechanical intervention at the time of death is of limited value, since death is considered a moment of destiny involving supernatural forces.”\textsuperscript{162}

B. End of Life Decisions in Islam

i. Euthanasia

Euthanasia is defined with moral distinctions made between passive versus active euthanasia. Passive euthanasia is thought of as simply allowing an individual to die, while the action of the physician who is removing supportive treatment gives rise to a situation in which a
life threatening illness or disease condition actually ends the patient’s life. Withhold ventilator support for breathing is a typical act of passive euthanasia because the individual would simply cease to be able to breathe without the ventilator. Active euthanasia, in contrast, involves performing some action that itself terminates the life of a person such as injecting an individual with a lethal dose of a drug at his or her request.

Islamic law clearly and definitively prohibits and forbids both active and passive euthanasia. Neither the Qur’an nor the Hadith speak about suicide but some theologians see 2:195 of the Qur’an as prohibiting it: “do not cast yourself into destruction.” Islam stresses the continuity of life beyond the grave and emphasizes as well the jurisdiction of God over life and death. This results in a situation in which Islamic physicians and Muslims in general resist the notion of assisted suicide. Muslims also tend to resist active voluntary euthanasia in the belief that “God will not burden a person beyond what they can bear (2: 286). However, if a burden does become unbearable, then the community’s role is to help alleviate it, but not by killing the individual.”

The sanctity of human life therefore prohibits active euthanasia but the right of the patient to refuse prolongation of life through artificial means when a terminal diagnosis has been given is protected under Islamic law. No one is authorized to deliberately end life and Islam “does not also recognize a patient’s right to die voluntarily because life is a divine trust and cannot be terminated by any form of active or passive human intervention, and because its term is fixed by an unalterable divine decree.”

Some Muslim jurists have held that in the case of adults and children a collective decision guided by three or more physicians not to prolong the life of an ill person is possible. The Islamic ethical rule – “no harm shall be inflicted or reciprocated in Islam” – is addressed in
this issue. Scholars have pointed out that this rule “allows for important distinctions and rules about life sustaining treatments in terminally ill patients; the distinctions on which ethical decisions are made include the difference between killing (active euthanasia) and letting someone die (passive euthanasia).”168

Research described by Tayeb, Al-Zamel, Fareed, and Abouellail employed a survey methodology with a sample of 284 Muslims of both genders with different nationalities and careers to consider issues related to aspects of death and dying as well as “death with dignity.” The study revealed that well over 85 percent of respondents firmly believed that in cases in which recovery is hopeless, the role of health care providers is modified because they need to help patients and families minimize suffering and maximize comfort by offering appropriate medical care that is neither excessive nor negligent.169

At the same time, this study indicated that many Muslims are increasingly sensitive to the notion that it is not strictly necessary for medical caregivers to use heroic measures in providing end of life care. This means in essence that what is thought of as passive euthanasia can in fact be permitted due to new understanding of medical treatment. Ebrahim noted that Islamic law is evolving at least to some extent with respect to this issue.170

There are, quite clearly, some significant differences between Islamic, Christian, Jewish, and other approaches to the issue of euthanasia. A central concern introduced by demands for euthanasia in Muslim countries centers on the effect of various fatwas, in which the scholarly study of end of life ethics is a very recent feature dating only to the 1980s. Van den Branden noted that Islamic views on non-voluntary euthanasia have not undergone any change at all in the past 30 or so years. Voluntary euthanasia is still regarded with suspicion by both Sunnis and Shi’ites, who base their conclusions on Quranic verses and prophetic traditions.171 This is the
case even when a patient is diagnosed as suffering from a terminal illness or condition that will lead inevitably to enormous, perhaps prolonged, pain and suffering.

Orthodox Islam has not changed its position on euthanasia. Sanctity of life is a paramount principle permeating all aspects of Islamic medical practice. “Islam recognizes that death is an inevitable of human existence. Thus, treatment does not have to be provided if it merely prolongs the final stages of a terminal illness as opposed to treating a superimposed, life threatening condition.”

When comparing Islamic medical ethics with secular principles, beneficence and non-maleficence are major and complementary goals. This means that suicide – undertaken with the deliberate assistance of a second actor or by the individual patient himself or herself – is not accepted in Islamic medical care.

**ii. Withholding/Withdrawing Treatment**

It is interesting that the Islamic prohibition against both active and passive euthanasia does not preclude decisions to withdraw or withhold treatment. As medical care itself has become more and more accessible in Saudi Arabia and other Islamic countries, new approaches to both the administration of pain relief preparations and the withdrawal of treatment have also emerged. These emerging views are not to be understood as the result of Westernization or modernization per se but rather as a transformation of understanding regarding the role that physicians can and perhaps should play in delivering services to the terminally ill and dying patient.

Withholding and withdrawing treatment is still contentious within the context of Islamic law. Babgi points out that the decision to withhold or withdraw treatment is determined in
Islamic care settings by a process through which the cost and benefits associated with treatment itself and the extent to which the treatment is considered to be futile is undertaken.\textsuperscript{173} This particular process is not, however, as cut and dried as one might assume. In fact, it can be quite complex to arrive at a decision regarding withdrawing or withholding treatment because of the association of such a decision with suicide or a violation of the ethical rule against inflicting or reciprocating harm.

The distinctions on which ethical decisions are made involving euthanasia versus forgoing treatment are important considerations. Sachedina states “there is no immunity in Islamic law for the physician who unilaterally and actively decides to assist a patient to die.”\textsuperscript{174} There are two instances that could be interpreted, as passive assistance in allowing a terminally ill patient to die that would not result in criminal charges being brought. First, a physician can administer pain relief that might shorten life but which is given to relieve physical pain and psychological distress. Secondly, Islamic law allows a patient to refuse a death delaying treatment; it also allows a physician after consultation with the patient, his or her family, and others involved to withdraw treatment on the basis of informed consent.

The Do Not Resuscitate (DNR) decision is acceptable in Islamic law under specific conditions. Takroui and Halwani state that a well-informed, mentally competent patient in Islamic societies is recognized as possessing decisionmaking capacity and, therefore, the right to refuse medical therapy. This includes treatments that would sustain life artificially. If a patient has made the decision to sign a DNR order and is deemed competent to have done so, physicians are not compelled for force treatment on an unwilling patient.

Ur-Rahman, Arabi, Adhami, Parker, and Al-Shimemeri stated that DNRs are widely accepted and practiced in Saudi Arabia. In the Kingdom, among patients who die while they are
hospitalized, between 70 and 84 percent have a DNR order on record. – despite the fact that there are currently no national medical guidelines concerning DNRs in the Kingdom. With the availability in the Kingdom of substantially improved and technologically sophisticated medical techniques and life support options, complex issues emerged regarding end of life care and the DNR option. The majority of physicians in the Kingdom appear to favor DNR as a physician directed decision.

Advanced directives or DNRs in the Kingdom are practiced and permitted in hospital settings. When two or three physicians determine that the situation of a patient is hopeless a DNR can be invoked either by the patient or a member of the patient’s family if the patient is a minor or a person with diminished capacity. This in turn allows a physician to withdraw or to withhold treatment. Research indicates compliance with DNR policies in Saudi Arabian hospitals is increasing and that more and more physicians are accepting this particular practice as not in violation of Islamic law.

The purpose of a will, an advanced directive or a DNR is to honor the autonomy of a patient and, coincidentally, to allow physicians to act as their patients want them to act. Such documents honor the autonomy of the individual. Said and Takrouni believe that a well informed and competent patient has the right to refuse medical treatment and that physicians and/or relatives should have this right in the case of a patient suffering a sustained coma. If the patient has made a decision to receive life sustaining therapy, or in those cases where such therapies were initiated, a DNR allows the patient to decide at any time whether or not such a treatment should be continued or withdrawn.

In the Islamic context, wills are exclusively used to identify an individual’s preferences for the division of material assets, burial requests and other issues. Such documents do not play a
role in establishing preferences regarding the withholding or withdrawal of medical treatment. Rarely would a family member or other surrogate be considered an appropriate decision-maker in this context because the law does not view them as sufficiently qualified or knowledgeable with respect to medical issues. Again, one must recognize the role of the physician in Islam—the physician is the individual whose expertise comes into play in first of all determining that a patient is in fact terminally ill and that no treatment can alleviate or ameliorate the condition causing this to occur.179

Saudi physicians do, however, actively encourage certain populations of patients to make efforts for advanced planning. Individuals who have been diagnosed with late stage cancer or whose cancers have progressed beyond repair or remission, individuals requiring hemodialysis in order to sustain life, or individuals afflicted with other diseases or conditions that cannot be changed, and for whom death is imminent, are encouraged to create advanced directives and DNRs.180

Decisions about advanced directives are influenced by many factors. These factors include prognosis, quality of life, socioeconomic support, patient’s beliefs, demographic variables, and medical knowledge.181 The decision to withdraw or withhold treatment in Islamic settings is therefore quite complex. Such decisions are to be made with the fundamental principles of Islamic law in mind and to ensure that pain and suffering are relieved without having participated in active euthanasia. The inevitability of death is recognized as a logical and legitimate end to material existence and while active euthanasia is not accepted, withdrawal of life sustaining treatment is often seen as allowing death to take its natural course.

Some Muslim jurists “recognize as legal a competent patient’s informed refusal of treatment or a living will which allows a person to die under circumstances in which there are no
medical reasons to continue treatment.”\textsuperscript{182} The next section of this chapter will examine in even greater detail the question of what is seen as constituting futile treatment under Islamic bioethics and law. Futility is certain significant in the context of withdrawing and withholding treatment.

\textit{iii. Futile Treatment}

Often, physicians face the necessity of acknowledging that any further treatment given to their patients would essentially be futile or, expressed more directly, would be incapable of providing any meaningful value to the patient with respect to improving his or her health status, curing a disease or illness, or otherwise prolong life while enhancing the inherent quality of life.\textsuperscript{183} As described by Zahedi, Larijani, and Bazzaz, futile treatment is widely recognized as treatment that has little likelihood of providing any meaningful benefit to a patient; however, many patients and their significant others often request continued treatment even when their physicians have informed them that such treatment will be ineffective.\textsuperscript{184} In many medical settings, the issue of futility is employed to inform the decision as to whether or not treatment should be withheld or withdrawn.

This particular issue was discussed Sayeed, Padela, Naim, and Lantos with respect to the case of a Saudi Arabian man whose infant was dying in the pediatric intensive care unit (PICU). This particular parent asked the primary care physician treating his two month old son to remove life support systems from the child and, as significantly, to refrain from informing his wife that this decision had been made. From a Muslim bioethics perspective, these researchers found that the father to a greater extent than the mother was aware of the futility for further treatment for a child who was minimally conscious with a relatively poor prognosis. The physicians caring for the child in the PICU at Boston Children’s Hospital expressed concern with the request that the child’s mother not be informed of the decision to withdraw life support.
According to Sayeed, et al, the physicians’ concern was not focused on withdrawing treatment or the futility of treatment. The physicians agreed that further treatment was unlikely to make any meaningful difference in the prognosis of the child.\textsuperscript{185} The researchers found that among Saudi families faced with a determination that further treatment of a loved one is futile, the decision to withdraw treatment is particularly burdensome and is often passed upon perceptions of the expertise of a physician. In addition, these researchers noted that in cases where a child is involved, the decision regarding the withdrawal of treatment in Saudi culture is generally made by the father, who is culturally positioned as the accountable head of the family and who is therefore empowered to make such decisions on behalf of his family members.

In discussing the withdrawal of treatment when additional treatment is seen by physicians as futile, Sachedina stated that Muslim physicians see withdrawal of life sustaining treatment as allowing death to take its natural course.\textsuperscript{186} Islamic law permits “withdrawal of futile and disproportionate treatment on the basis of the consent of the immediate family members who act on the professional advice of the physician in charge of the case.”\textsuperscript{187} Some Muslim jurists acknowledge the legality of a competent patient’s informed refusal of treatment or a living will in these circumstances. However, even in such cases acknowledging the autonomy of the patient in Muslim culture, “the law takes into consideration the patient’s long-term treatment relationship with a physician whose opinion, in the final assessment, serves as the grounds” for withdrawing treatment.\textsuperscript{188}

Zahedi, Larijani, and Bazzaz pointed out that acknowledging the futility of treatment is a challenging and controversial issue for many Muslim physicians, health care institution administrators, jurists, and patients.\textsuperscript{189} The most important question that is asked centers on futility: is the treatment being given to the patient futile or not? Resorting to futile treatments in
order to stave off death is not considered to be acceptable in Islam. If, on the other hand, there is any desirable reason for continuing the treatment, decision making is difficult when resources are limited. The issue is particularly troubling in the case of young children in that children are valued and respected in Islam “with inherent rights and they have the right to be treated with respect and without violence.”

With the emergence of improved palliative care services in Saudi Arabia and other Muslim countries, decisions regarding the withdrawal of life support measures employed with children as well as adults have been eased somewhat. The issue of resources is significant in making decisions regarding end of life care and life sustaining treatments in terminally ill patients. However, as Zahedi, Larijani, and Bazzaz have pointed out, “some Muslim scholars suppose that patients or their guardian may refuse treatments that do not in any way improve their condition or quality of life…. They argue that the reason in this instance is that delaying the inevitable death of a patient through life sustaining treatment is neither in the patient’s nor the public’s best interest because of limited financial resources.”

C. The Health Care System in Saudi Arabia

1. Status of the Saudi Arabian Health Care System

Amir A. Khaliq offered an extensive review of the origins history, evolution, and current status of the health care system in Saudi Arabia pointing out that this system is “currently being transformed from a publicly financed and managed welfare system to a market oriented, employment based, insurance driven system.” Created in the 1920s, the system has provided free health care to all Saudi nationals at publicly owned, government run facilities. For the millions of foreign workers in the Kingdom, health care at privately owned, for profit facilities is financed either by employers or the individual. At the end of what promises to be a fairly
lengthy process, and at the conclusion of a three stage transition, all people in the Kingdom regardless of citizenship status or employment sector will have insurance coverage provided by their employers and all Ministry of Health owned hospitals will be divested to the private sector with primary health care centers probably retained by the government.\textsuperscript{194}

The government of the Kingdom has over the last 95 years given high priority to the development of health care services at the primary, secondary, and tertiary levels. The end result is that the health status of the Saudi population has improved significantly in recent decades. Nevertheless, a number of issues have been identified as posing challenges to this system including:

- A shortage of Saudi health professionals in all health care specialties.
- Limited financial resources.
- The Ministry of Health’s multiple roles as provider of services and overseer of private sector activity.
- Absence of a national crisis management policy.
- Lack of a national health information system (HIS).
- Poor accessibility to some health care facilities, particularly in non-urban regions of the country.

These challenges notwithstanding, advances in the health care system have been forthcoming as a consequence of increased governmental commitment to health care services, improved education among Saudi nationals, economic growth, and heightened awareness of health issues. It has been estimated that in 2010, the government in the Kingdom spent about 3.3 percent of its gross domestic product (GDP) on health care; World Health Organization (WHO)
statistics for 2008 indicated that the country spent US $621 per person on health care, of which 77.6 percent was paid for by the government and 16.3 percent was an out of pocket expenditure.195

Health indicators for Saudi Arabia depict significant improvements in the overall health status of the country. The WHO ranked Saudi Arabia 26th among 190 member states on overall performance of the health care system, 61st on goal attainment, 58th on the basis of disability adjusted life expectancy, and 63rd on health expenditures per capita in international dollars.196

More recently, out of 182 countries with comparable data, Saudi Arabia was ranked 59th on the Composite Human Development Index (HDI), a comparative measure of well-being based on the criteria of life expectancy, adult literacy, and the standard of living.

Data presented below, provided by Amir Khaliq, provide an overview of various factors relevant to healthcare in Saudi Arabia.

<table>
<thead>
<tr>
<th>Table 1. Demographic, economic and health related data for Saudi Arabia and five other countries in the region</th>
</tr>
</thead>
<tbody>
<tr>
<td>Saudi Arabia</td>
</tr>
<tr>
<td>Area in square kilometres</td>
</tr>
<tr>
<td>Total population in millions</td>
</tr>
<tr>
<td>Population growth rate</td>
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<tr>
<td>Population under 15 years of age</td>
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<td></td>
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<td>--------------------------------</td>
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<tr>
<td>Adult literacy rate</td>
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<tr>
<td>GDP per capita (current $)</td>
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<tr>
<td>Expenditure on health as % of GDP</td>
</tr>
<tr>
<td>Health expenditure per capita</td>
</tr>
<tr>
<td>Out-of-pocket spending as % of total health expenditure</td>
</tr>
<tr>
<td>% of population with access to safe drinking water</td>
</tr>
<tr>
<td>Life expectancy at birth (in years)</td>
</tr>
<tr>
<td>Infant mortality per 1000 live births</td>
</tr>
<tr>
<td>Maternal mortality 100,000 births</td>
</tr>
<tr>
<td>Total fertility rate per</td>
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<tr>
<td></td>
</tr>
<tr>
<td>---</td>
</tr>
<tr>
<td>woman</td>
</tr>
<tr>
<td>% of one-year-old children vaccinated for measles</td>
</tr>
<tr>
<td>Married women using some form of contraception</td>
</tr>
<tr>
<td>No. of hospital beds per 1000 population</td>
</tr>
<tr>
<td>No. of physicians per 1000 population</td>
</tr>
<tr>
<td>No. of nurses and midwives per 1000 population</td>
</tr>
</tbody>
</table>

GDP = gross domestic product.

*The data reported in this table cover years 2003–2009 and are not for the same year in each of the columns or the rows. These data are reported only to provide a comparative context for Saudi Arabia.*

Table 2, below (also provided by Khaliq), presents data regarding financing of healthcare in the Kingdom.
<table>
<thead>
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</tr>
</thead>
<tbody>
<tr>
<td>Health expenditure as % of GDP</td>
<td>3.5%</td>
<td>4.3%</td>
<td>3.3%</td>
<td>3.4%</td>
<td>3.6%</td>
</tr>
<tr>
<td>Government spending on health as % of total health spending</td>
<td>80.2%</td>
<td>71.6%</td>
<td>77%</td>
<td>79.5%</td>
<td>68.2%</td>
</tr>
<tr>
<td>Private sector spending on health as % of total health spending</td>
<td>19.8%</td>
<td>28.4%</td>
<td>23%</td>
<td>20.5%</td>
<td>31.8%</td>
</tr>
<tr>
<td>Government spending on health as % of total government spending</td>
<td>9.4%</td>
<td>9.2%</td>
<td>8.7%</td>
<td>8.4%</td>
<td>8.4%</td>
</tr>
<tr>
<td>Per capita government spending on health in US$</td>
<td>–</td>
<td>276</td>
<td>379</td>
<td>422</td>
<td>461</td>
</tr>
<tr>
<td>Per capita government spending on health in PPP$</td>
<td>297</td>
<td>520</td>
<td>559</td>
<td>610</td>
<td>567</td>
</tr>
<tr>
<td>Per capita total spending</td>
<td>260</td>
<td>386</td>
<td>492</td>
<td>531</td>
<td>676</td>
</tr>
</tbody>
</table>
Indicators regarding the health care system in Saudi Arabia and its capacity for meeting health needs were also provided by John Baranowski who stated that “a 20 percent increase in population by 2016 alone is certain to tax the already challenged health care system.” Despite the anticipated transition to privatized health care services, the current system provides a national entitlement for citizens only rather than a procured protection. The success of the Saudi approach to providing national health care is based in large measure on the willingness and the capacity of the Al Saud royal family to finance such a system.

The problem, said Baranowski, is that “because of the seemingly endless royal cash flow little desire or effort is committed toward efficiency and/or self-sufficiency.” Equally important is the fact that Saudi citizens are now demanding improved health care services and improved access to cutting edge and state of the art health care services. Research suggests that the annual population growth rate in the Kingdom is 2.7 percent with a total fertility rate of 3.8 percent. Life expectancy increased from 52 years in 1970 to 72 in 2005 and a compulsory vaccination program implemented in the 1980s resulted in a reduction of the under five years of age mortality rate from 250/1,000 live births in 1960 to 26/1,000 in 2005.
The Ministry of Health is the major governmental entity involved in strategic planning for health services, the formulation of health policies, supervision and the monitoring of all health related programs and activities within the Kingdom. Over the past two or so decades, health care in the private sector has increased in the Kingdom to serve a population of 27.1 million people, but a market oriented system has not as of yet fully emerged. The latest data indicate that there are 331 hospitals with 47,018 beds along with 2,838 primary health care centers that are staffed by 19.0 physicians, 2.10 dentists, 3.40 pharmacists, and 35.0 nursing and midwifery personnel per 10,000 individuals.202

Despite progress, there have been a number of criticisms levied against the Saudi health care system. For example, research indicates that critical care medicine remains underdeveloped in Saudi Arabia, a problem that is exacerbated during the Haj season when millions of Muslims make a pilgrimage to Makkah and Medina.203 Further, while palliative care directed toward improving the quality of life of patients and their families facing problems that are associated with life threatening and/or terminal illness has emerged as a vital specialty, the Kingdom is said to lag behind in preparing physicians for palliative care treatment protocols. This may be due in part to the religious and cultural attitudes of Muslims regarding the role of suffering.204

There is also a recognized need in Saudi Arabia for hospital based neonatal palliative care programs. This end of life care is absent in the neonatal intensive care units in the Kingdom, none of which have adopted such a program.205 The reason most often given for this deficiency is a lack of knowledge along with the fear of being accused of heartlessness and cruelty by providing comfort care for dying babies. Equally significant, perhaps, is the fact that many Saudis are reluctant to address issues regarding end of life care and many physicians are uncomfortable with informing parents that their child is terminally ill. These are some – but
hardly all – of the challenges confronting the national healthcare system in Saudi Arabia. Other challenges are linked to national culture and the impact of religious belief and value systems on the practice of medicine.

ii. Cultural Context

The culture of Saudi Arabia derives from a number of factors, not the least of which is the monolithic status of Islam. As described by Kwong and Levitt, cultural characteristics of Saudi Arabia are influenced by the importance of personal relationships, a hierarchal social structure, and religion.\textsuperscript{206} The Islamic religion derives some but not all of its traditions and values from the tribal system which also serves to determine the power structure of the Kingdom and to exert influence on government policies including those of the Ministry of Health.

Further, there are two legal systems in Saudi Arabia. One is based on Shari’a or Islamic teachings and the other is based on secularized or non-religious laws known as \textit{nizam}. These regulations are issued by the King via the exercise of political legislative power which has important implications for professional organizations which must deal with two sets of laws that are often contradictory. As Kwong and Levitt point out, “having two sets of laws has caused confusion and frustration which have resulted in settling disputes out of court or by the Ministry of Health.”\textsuperscript{207}

Saudi Arabia is an oil rich and autocratic country that has adopted an extremely and at times repressively paternalistic attitude toward its citizenry. The Basic Law of the Kingdom does not, for example, guarantee gender equality and in fact, gender inequality “is built into Saudi Arabia’s governmental and social structures, and is integral to the country’s state supported interpretation of Islam which is derived from a literal reading of the Koran and Sunna.”\textsuperscript{208} A substantial majority of Saudi citizens agree with the social agenda of the state
funded body of religious scholars known as the *ulema* with respect to gender relations which position men and women as legitimately active in two different spheres.

However, Doumato reports that there is a vigorous progressive movement emerging in the Kingdom that is seeking to eliminate inequalities between men and women and to improve women’s bargaining power in Islamic family law courts. Women’s lack of mobility within the Kingdom and restraints on their capacity for traveling abroad are troubling to many Saudis as is the fact that women are not as yet permitted to vote in the Kingdom’s municipal elections. Further, with respect to the issues addressed herein, Saudi women have been characterized by Nader Said-Foqahaa as deprived of interfamilial decisionmaking capacity due to patriarchal authority.

In the context of health care decisions, Saudi women encounter challenges to their autonomy as is the case in other areas such as education, employment, and marriage. Said-Foqahaa notes that in multiple circumstances, Saudi women are expected to defer to decisions made on their behalf or impacting on them by their fathers, husbands, guardians, or other male relatives. The system provides tools “for controlling women and keeping them in their ‘natural place.’”

The issue of women’s rights and autonomy becomes significant in this discussion. Patriarchal societies such as that of Saudi Arabia tend to limit the ability of women to participate on an equal footing with men in terms of decision-making. Saudi women, for the most part, are forced to rely upon the decisions made on their behalf by a father, husband, or other male guardian. This is as true in the case of health care as it is in terms of other decisions such as attending university, leaving the country, or working for pay outside of the home. While it is true that this situation is gradually changing as more and more Saudis are being educated abroad –
and as the Al Saud monarchy extends legal rights for women in the Kingdom, including the right to drive an automobile and to vote in local if not national elections - such changes are admittedly gradual and are not necessarily directly impacting upon the great mass of Saudi women.

Even in cases where a Saudi woman patient is being treated by a female physician, the final decisions regarding her health are not generally left to her.\(^{213}\) Much the same thing can be argued regarding decisions on behalf of minor children. Saudi mothers have less influence over such decisions than do their spouses or male guardians and their attending physician. Again, this is due to patriarch and to the fact that a physician in Saudi Arabia is viewed as a person possessed of expert authority who must be respected and whose advice must be followed. Within the context of a family relationship, of course, Saudi women may actually exercise more authority and decision-making capacity than is generally recognized. There are certainly variations in this phenomenon.

Additionally, it is important to recognize that in Saudi culture in general, the principle of autonomy related to personal health care decisionmaking is nowhere near as well established as it is in Western culture. The Western secular model is "a modern phenomenon conceived in the 1970s to address new ethical dilemmas in medical practice and biomedical research" that was "grounded in secular, philosophical principles relying on human reason and human experiences."\(^{214}\) Autonomy stands, to an extent, in opposition to the collectivist nature of Saudi society in which the individual is largely subordinate to the family, the clan, the tribe, and so on.

It may well be that secularism is antithetical to the collectivist societal structure.\(^{215}\) Alternatively, one could argue that Islam itself fosters a collectivist orientation. The Muslim is required to submit to God, and in so doing to acknowledge the subordination of the self to a larger and more powerful Being. This can easily be transferred into here-and-now societal
relationships. Between the individual and the world, one finds the collective, and the collective is led (and in some instances ruled) by an individual given authority to make decisions on behalf of the members of the collective. Such a system is supported by religion and is incompatible with secularism.

The Islamic model differs from the Western model in its emphasis on the guidance of God as the guiding principle in personal decision making and its acknowledgement of moral principles directly applicable to medicine. With no separation between state and religion, no activity is considered to be purely secular in the life of a Muslim. Individual autonomy is not viewed in Saudi culture as on a par with the principles of Islam and “the rights of God, the community, and the individual factor in any decision, as is the overriding need for beneficence reflected as a call to virtue and nonmalificence reflected by abstention from harm.”

One must constantly be aware of this critical feature of Saudi society if one is to understand how a Saudi physician acquires and employs authority in terms of determining patient care. This becomes especially significant in terms of end of life care. Submission to the will of God regarding termination of life may be integral to Muslim belief, but the actuality of a terminal illness may well evoke fear and resistance. Consequently, empowering physicians to make decisions regarding this care removes the burden from patients and their family members.

Physicians in Saudi culture have the obligation of dissuading their patients from hazardous lifestyle and behavioral choices that undermine collective well-being. Physicians are also seen by Saudis as figures of authority and both male and female Saudis tend for the most part to defer to the authority of a physician with respect to many aspects of health care decisionmaking. As noted above, many Saudi physicians communicate with the male head of
household in navigating hard choices impacting on health, treatment, and end of life decisions. Women are unlikely to be consulted in such cases.

Saudi culture is almost entirely shaped by Islam. Islamic practice is “connected to spirit, behavior, food, language, and social traditions.”\textsuperscript{218} With a health care system that is developing rapidly and becoming increasingly dependent upon Westernized medicine and medical practices, it is reasonable to conclude that there will be change forthcoming with respect to many aspects of medical practice in Saudi Arabia. Kwong and Levitt stated that “due to rapid shifts in the country, especially following the recent increases in oil prices, the government has shown interest in issuing a new set of rules and ethical codes, and other procedures to enhance the quality of care.”\textsuperscript{219} That said, it is highly unlikely that the inherently patriarchal, hierarchal, and collectivist culture in the Kingdom will undergo any meaningful changes in the foreseeable future.

iii. Saudi Arabian End of Life Care Practices

As Sachedina pointed out, Islam considers it fundamentally important that one submit all aspects of one’s personal and social life to the will of God. This feature has placed ethical reflection centrally within Islamic thought and directly impacts upon Saudi Arabian end of life care practices.\textsuperscript{220} Ethical doctrines underpinning medical practice and the field of bioethics in Saudi Arabian culture are derived entirely from Islam itself, which does share a common moral terrain with secular bioethics with specific reference to the necessity of practicing beneficence in the care of patients.

Sachedina argues further that end of life care practices in Islam must embrace the concept of the public good and the important concept of preventing harm and promoting good.\textsuperscript{221} It is this orientation that inevitably is associated with the development of palliative care programs in
Saudi Arabia. Palliative care refers broadly to care that provides for an increase in comfort and a reduction in pain and suffering in cases where an individual experiences terminal illness or confronts a likely death as a consequence of trauma or accident. It includes more than alleviating physical pain. It encompasses emotional, psychological, social, and spiritual pain reduction as well. Issues relating to spirituality include religious beliefs and practices that can come to the forefront in patients experiencing advanced illnesses. Spirituality and religion, according to Aljawi and Harford are “coping mechanisms” which means that “health care providers should possess cultural and religious knowledge and sensitivity relevant to the patients being treated.”

In Saudi Arabia, localized provision of palliative care is emerging but at this particular point there is no national set of standards or practices impacting upon the provision of such care in the Kingdom. Palliative care began to be practiced in Saudi Arabia some 20 years ago as part of a program designed to accommodate adults and children with life limiting conditions. To date, the great majority of clients receiving services in the palliative care programs in Saudi Arabia are adults with advanced cancers although some health institutions are pursuing staff specialization in pediatric palliative care. Many Saudis still exhibit a distinct preference for experiencing the end of life in their homes in the company of relatives, a preference that is associated with such factors as a negative attitude towards some of the instruments and practices that are used in controlling and minimizing pain or out of a simple desire to die privately in the company of loved ones.

Research on patterns and outcomes of hospital based palliative care unit admissions in Saudi Arabia sheds light on this issue. A retrospective review to assess the patterns and outcomes of such admissions was undertaken by Alsirafy, Hassan, and Al-Shahri. These
researchers reviewed 759 eligible palliative care unit admissions related to a total of 629 Saudi Arabian cancer patients. A four-year period was considered. Of all admissions, some 66 percent were hospitalized through the emergency room and patients had an average hospital stay of 24 days. The majority – some 86 percent – of patients died in the hospital.226

Of the 14 percent of the subjects in this study who did in fact die during the course of the study period and who chose to remain at home, the majority indicated that they preferred to be in the company of loved ones and relatives rather than in the somewhat more open and less private environment of the hospital. Some patients indicated that they were reluctant to discuss issues regarding death and dying while others felt that they were often forced to accept or undergo medical treatments that they did not wish to experience or which they believed were of limited benefit to them. Further, Alsirafy, Hassan, and Al-Shahri pointed out that some of their subjects felt that their physicians were not forthcoming in communicating the diagnosis of a terminal illness and that continued treatment offered false hope.227

Critical care medicine in Saudi Arabia remains relatively underdeveloped, an issue that was touched upon above. Research suggests that the central thrust of critical care medical practices in the Kingdom is on doing no harm and prolonging life. Unfortunately, there are no national standards in Saudi Arabia regarding critical care medicine or end of life practices. This creates a situation in which there are often extensive variations in the approaches taken to end of life care practices in the Kingdom. This means that much of the care given at this critical juncture depends upon the knowledge, skills, and attitudes of physicians who exert significant influence over patient decisionmaking at this juncture.228

Research suggests that medical caregivers in Saudi Arabia are well aware of the necessity of improving resource utilization in intensive and critical care units and with respect to palliative
care offered to terminally ill and dying patients. One research team suggests that in the face of increasing demands for intensive care services in the country, along with the high costs of delivering such services, it is becoming increasingly necessary to take systematic steps to ensure optimal utilization and fair allocation of resources. Strategies should begin prior to intensive care unit admissions with the proper selection of patients who are likely to benefit from intensive or critical care unit services. It is also recommended that do not resuscitate status in patients with no meaningful chance of recovery be considered in order to prevent futile admissions to such units.229

Of course, measures to improve the efficiency and quality of care in critical and intensive care units are also needed in this particular country as is the introduction of evidence based management protocols. The difficulty that has been identified with respect to Saudi Arabian end of life care practices and more efficient utilization of intensive and critical care units is the reluctance of some physicians to communicate to patients that an illness is terminal and that nothing further in the way of treatment will be of value.

Aljubran stated that physicians in Saudi Arabia often find that disclosing a diagnosis or prognosis to cancer and other terminally ill patients is a serious challenge for physicians. This is due in part to the fact that the public attitude toward full disclosure remains conservative. In order to deal effectively with such an attitude, it is necessary for physicians to gain insight into its sociocultural background. Aljubran states that while Saudi Arabians and other Muslims acknowledge the inevitability of death, the religion itself focuses on the value of life and the corresponding necessity of submission to the will of God.230

Saudi physicians may also feel conflicted over the fact that their mission as physicians is to enhance the quality of life while alleviating suffering – even though Muslims accept the
inevitability of suffering and see it as a form of atonement for sin. Many physicians are looking toward organs of the state such as the Ministry of Health for guidance on appropriate practices with respect to end of life care. The deficits in such standards are readily apparent according to Alamri when one examines knowledge of residents at a major Saudi hospital about palliative care. Alamri used a cross-sectional design to query a total of 80 residents at King Abdul Aziz University Hospital (KAAUH) on palliative care, with 65 or 81 percent responding.

As briefly discussed earlier, the research found that resident physicians at KAAUH enrolled in postgraduate programs had suboptimal knowledge of basic palliative care. The study indicated that residents in internal medicine, emergency medicine, and surgery had significantly more and better knowledge about palliative care than their colleagues in such specialties as dermatology and ophthalmology. However, the problem identified by Alamri included the fact that most respondents to the survey indicated that they had received limited education on palliative care methods as medical students or as interns and that the subject was not often discussed during their residencies with attending physicians.

A study by Almuzaini, Salek, Nicholls, and Alomar sought to assess cancer care and the need for establishing hospice and palliative care for cancer patients and their caregivers in Saudi Arabia. A sample of 695 participants was developed, of which 136 were cancer patients, 161 were informal or lay caregivers, and 398 were health care professionals. All subjects were recruited from oncology centers in four major regions of Saudi Arabia. Three different questionnaires were developed and administered individually to each group. Research revealed that the level of cancer care and end of life or hospice services in the Ministry of Health hospitals
was considered by all three groups to be poor when compared to hospitals such as the King Faisal Specialist Hospital, military hospitals, or university hospitals.

Results also suggest that regional hospitals failed to provide adequate home health care services or regular follow-up services. The shortage of drugs used in cancer management, a severe restriction regarding the prescription of narcotic analgesics, and the lack of cancer care knowledge were also identified as major impediments to providing good cancer care and good end of life care. These researchers concluded that the strong interrelationship among Saudi families, combined with the poor status of cancer care and cancer patients’ and their carers’ acceptance of hospital services illustrated the need for initiating better palliative care services in the Saudi health system. Finally, the study also underscored the need to provide palliative care training to Saudi health professionals to overcome knowledge deficits.²³⁵

The World Health Organization (WHO) has called for global implementation of a public health strategy of palliative care to reach everyone in a country’s population through:

- Appropriate government policies.
- Adequate drug availability.
- Education of the public, policymakers, and health professionals.
- Implementation of a national palliative care program.²³⁶

In the view of the WHO, Saudi Arabia must be considered among those countries in the world where there is a pressing need for improved end of life and palliative care practices. The problem is exacerbated by the fact that there are still many individuals in Saudi Arabia and elsewhere who lack personal information and knowledge about such diseases as cancer or who have cultural beliefs about the normalcy of pain and suffering that may cause them to delay
seeking care. The end result is that late presentation in hospitals with pain, no option of cure, and poor supportive care is all too common. What this then means is that it is increasingly important for the government to create more effective end of life care protocols for at risk populations.237

Reference was made earlier in this chapter to the issue of how physicians approach issues related to palliative care and end of life decisions in pediatric intensive care units. As Sayeed, Padela, Naim, and Lantos suggest, many physicians faced with the necessity of delivering a bleak prognosis to a Saudi family regarding their child prefer to interact directly with the father rather than with the father and mother together.238 Many Saudi fathers feel that they are better equipped to make decisions of this kind than are wives and mothers who are more likely to want to prolong life beyond the point where it is reasonable to do so. The Islamic biomedical perspective supports the decision of a father to make such determinations without involving a mother.

One of the real deficits in the Kingdom, therefore, is the lack of a broad understanding of palliative care and how it is often more kind and beneficent to limit decisionmaking in such instances to a single parent. This of course speaks to issues regarding the relative roles of men and women in Saudi society and the fact that children are viewed as under the guidance and control of their fathers rather than their mothers.

Conclusion

This chapter serves to illustrate a number of the unique characteristics of the Kingdom of Saudi Arabia that are directly relevant to end of life care practices. It seems readily apparent that no discussion of such an issue can be undertaken without a thorough understanding of how Islam and its tenets and ethical and moral belief and value systems directly impact upon medical care. As Dana Al Husseini has written, Islam permeates each and every aspect of life in Saudi Arabia.
and other predominantly Muslim countries. Shari’a or revealed law that is designed to regulate and evaluate human conduct is highly influential in determining the actions of Saudi physicians and other medical caregivers and in providing the foundation on which biomedical ethics are to be based.

The Qur’an, the Sunna, and legal reasoning in the form of unanimous consensus and analogy practiced by Muslim scholars are the roots of the law that influence this particular set of practices. Islam encourages its followers to care for themselves and to not lose hope even when given a terminal diagnosis while nevertheless confirming that everything is predestined and known to God. The Prophet Muhammad said that medicines and talismans are part of God’s power and that all human problems are predestined by God who asks man to make an effort in order to overcome them.

Thus, many Muslims accept illness and its attendant pain and suffering as unavoidable, which has led to some resistance to the use of analgesics in order to remove or reduce pain even in cases where an individual is recognized as terminally ill. Some physicians have gradually begun the process of creating effective end of life and palliative care protocols that simultaneously do no harm while relieving suffering. Nevertheless, the research suggests that more needs to be done with respect to this particular issue and that end of life care remains somewhat unfocused in the Kingdom.

The next chapter of this study will look at a very different cultural system and the ways in which that system approaches end of life care. It is to be expected that there will be substantive differences between the ways in which end of life care is approached in Saudi Arabia and the United States. It is further anticipated that these differences will be due in large measure to the normative influence of Islam and the fact that Islam underpins all aspects of life in the Kingdom.
Thus, the two countries provide for an excellent opportunity to compare cultures and to explore
the ways in which medical practices are shaped and influenced by culture.
Chapter Four

Comparison between Intensive Care Systems in the United States and Saudi Arabia

Introduction

An integral element within end of life care in most countries is the hospital based intensive care system. The intensive care unit (ICU) in any modern hospital provides a variety of services that are not necessarily limited to the terminally ill, but which are certainly used to a great extent by such individuals and their families.\textsuperscript{242} The ICU in the vast majority of contemporary hospitals in both the West and elsewhere is a central point at which end of life care is delivered to individuals and other supporting services are provided to their families. Although many patients end their lives in hospice settings, it is likely that the majority of dying patients will be cared for in ICUs. Consequently, in considering ICU care systems, one must inevitably acknowledge the role that is played by culture in shaping the practices of such a unit.

Critical care medicine is inevitably more costly than other services offered in hospitals. According to Halpern and Pastores, in the United States alone, between 2000 and 2005, annual critical medicine costs increased from $56.6 to $81.7 billion. This represented 13 percent of hospital costs, 4.1 percent of national health expenditures, and 0.66 percent of gross domestic product (GDP).\textsuperscript{243} The high cost of critical care medicine is but one part of the complex set of issues related to provision of services in ICUs. As one would expect, culture is a significant determinant not only of the attitudes of patients in an ICU and their families; it is also a fundamental element in shaping the principles of biomedical ethics that will be normative in such care settings.
One must nevertheless consider the role played by cost and expense issues in end-of-life care. One of the most significant healthcare sector “movements,” so to speak, of recent years in the United States centers on cost containment. New medical technologies are exciting in terms of their capacity for enhancing the quality of life and eliminating much pain and suffering, as well as extending life for the terminally ill patient. These technologies are not, however, inexpensive, and ensuring that there is anything resembling equality of access to such technologies and their related treatments is problematic at best. When a medical institution is called upon to simultaneously expand access and reduce costs of service delivery, problems inevitably emerge.

Certainly, biomedical ethics call for rising above considerations of cost as physicians and their medical institutions for about the business of delivering care. That said, it is necessary to recognize that there are conflicts between the duty of care and the necessity of cost containment. Even the most lavishly funded medical institution cannot be unaware of the escalating costs of some services – including, of course, end-of-life care that prolongs life without adding to its quality or resulting in anything resembling a cure or a meaningful remission. ICUs are constrained in this manner.

In point of fact, Gavrin made the case that there are few places in a hospital where biomedical ethics are not more significant than in the ICU. In the ICU, physicians, nurses, healthcare supportive staff, patients themselves (to the extent that they are considered competent to participate in decisions regarding their treatment), and family members are all challenged to make decisions that will impact dramatically upon the patient. Among the principles that come into play in such situations are concepts of beneficence and the fundamental mandate to do no harm. Sadly, one must acknowledge that beneficence is at times an ideal rather than a reality;
this is likely to be particularly true in cases where limited resources prevent an institution from delivering palliative care or hospice care. These issues will be addressed in this and other chapters of the study.

This chapter of the study is designed to compare ICU systems, practices, and norms in the United States and Saudi Arabia. It also serves to explain the rationale for incorporating elements of the American system into the Saudi Arabian system. It should be acknowledged at the outset of this chapter that when Saudi Arabia and the United States are compared, one is comparing two very different countries with very different cultures and, consequently, very different ethical and normative systems.\textsuperscript{248} Failing to acknowledge that the cultures of the two countries are primary influences on their respective health care systems cannot be permitted. Culture matters and is normative, regardless of which country or what variety of culture one is addressing.

A. The United States

The United States has long recognized the significance of the ICU and the need for a system for providing critical care services to individuals many of whom are terminally ill and confronting the immediacy of death. In fact, research demonstrates that such specialized care units in U.S. hospitals have been common for well over 50 years.\textsuperscript{249} The ICU provides for critical care management of a variety of conditions among which in the United States respiratory insufficiency/failure, postoperative management, ischemic heart disorder, sepsis, and heart failure, are the five primary admission diagnoses in decreasing order. Since about 1991, the treatment of a variety of serious conditions has become more frequent with ICUs addressing gastrointestinal hemorrhage, hemodynamic abnormalities, respiratory insufficiency or failure, multiple organ system failure, shock, and sepsis.\textsuperscript{250} These are some but hardly all of the
conditions that are addressed in the context of an ICU; many post-surgical patients experiencing no negative effects from their surgery also spend time in an ICU, where the level and type of care they receive is more constant and focused than it can be on a hospital ward.

The expansion of ICU services in the United States is due in part to the fact that the population of the United States is aging and it is expected that as the baby boomer generation continues to age, more and more Americans will need the services of an ICU. In fact, today, the ICU is the locus of approximately 25 percent of all deaths occurring in the United States. ICU expenditures comprise about 34 percent of the total budget of any hospital and as noted above account for 0.66 percent of GDP. The ICU is, consequently, one of the most costly sources of medical care in the United States today. In an era that is characterized by efforts at cost containment while simultaneously increasing outreach to underserved populations, the ICU clearly has enormous significance as part of the U.S. healthcare delivery system. (Again, one must realize the role played by the move toward managed care and its close relative, cost containment.)

Just as significant is the fact that while the ICU is a literal hospital hotspot with respect to the kind of care delivered and the seriousness of the life and death issues that regularly occur on this unit, caregivers in this setting also must address the question of bioethical decisionmaking. Medical ethics in the United States has become a topic of significance for any number of reasons to be discussed below. Jonsen suggests that there are few places in an American hospital where ethical and moral decisions are more likely to be made than in an ICU. This suggestion is legitimate as more Americans are likely to die in an ICU than in any other hospital setting – including hospices.
Ethical decisionmaking in this particular setting, therefore, inevitably involves both care
givers and care recipients and/or their significant others. Decisions made at this inflection point are, in a very literal sense, critical decisions. Because this is the case and because many patients in the ICU are themselves unable to make decisions on their own behalf, a variety of actors are involved in this process. This leads to an important question: who makes such decisions? Are these decisions the sole purview of physicians or institutional ethics committees? Are they legitimately the kind of decision that should be solely made by a patient and/or his or her family? Many U.S. institutions have committees that participate in such decisions.\textsuperscript{254}

Rivera, Dasta, and Varon argue that the ICU represents the hallmark of highly competent modern hospitals, “offering highly trained staff and lifesaving technology and it is also one of the most expensive units in the hospital.”\textsuperscript{255} The United States health care budget is seen by these analysts as demanding but also as having the smallest contribution from government taxation revenues when it is compared to other modern, industrialized countries. Despite the much-publicized controversies of healthcare reform and Medicare and Medicaid programming, the financing of healthcare and ICU services in the United States occurs primarily through private health insurance and consumer out of pocket finance. What this means, according to Rivera and colleagues, is that many families find themselves challenged to provide the financial wherewithal needed to support long term ICU resource use.\textsuperscript{256}

Efforts have been made to reduce these costs. These efforts include reducing the length of stay in the ICU by means of such techniques as fast track anesthesia, early extubation, and reducing normal levels of glycaemia in the critically ill patient in an effort to reduce the predisposition to suffer from neurological, cardiovascular, and infectious outcomes which are common in hyperglycemic patients. Equally important, however, in the view of any number of
researchers including Luce and White is coming to terms with the necessity of terminating life support treatment that will only prolong life without changing a patient’s prognosis. This particular strategy not only reduces the cost of ICU services, but can also prevent unnecessary pain and suffering.\(^{257}\)

Some research indicates that healthcare in the United States has failed to adequately address the need of a growing population with serious and eventually fatal chronic illnesses. Shugarman, Lorenz, and Lynn, for example, take the position that technology has far outstripped ethical decisionmaking and that as life expectancy for men and women in the United States increases, decisions regarding the allocation of medical resources are becoming more and more challenging.\(^{258}\)

The fact that more than 75 percent of U.S. citizens now live past the age of 65 and as of 2000, the average life expectancy was 80 years for women and 74 years for men is an indication of the probability that ICU costs will increase over time. Nearly one half of all American citizens have one or more chronic conditions that require care to prevent or to delay disability. What this means ultimately is that virtually “all United States citizens will have a substantial period of serious illness and disability at some point before death.”\(^{259}\) Thus, many forces have converged in the United States to make good care during fatal chronic conditions a national priority. The costs of chronic illness are certainly driving concerns for the government, private insurers, and individuals. Simultaneously, improving overall access to palliative care and hospice services is a national priority as well.\(^{260}\)

In addition to ICUs, hospice care in the United States has taken on enhanced significance. End of life care is being provided in a number of disparate settings but hospices are increasingly significant as a more cost-effective alternative to ICUs.\(^{261}\) Hospice care is a relatively recent
phenomenon in the United States but it is a viable alternative to prolonged stays in ICU units that tend to be much more expensive and treatment intensive. Beginning some 25 or more years ago, hospice development emerged as a critical policy priority in the United States healthcare system.262

Other significant issues in the United States in this general context include ensuring that people will have access to the ICU. Halpern and Pastores stated that there were more than 6,000 hospitals in the United States providing over one mission staff beds to patients.263 All acute care hospitals in the United States have at least one ICU. Somewhere in the neighborhood of 60,000 critically ill patients are cared for each day in some 70,000 or so adult critical care beds. Additionally, the U.S. has an extensive system of pediatric critical care units offering about 5,000 beds as well as neonatal intensive care units with over 20,000 beds. These data certainly illustrate the significance of critical care medical services in the United States and the extent of such services.

i. Decisionmaking in the ICU

There are many different decisions that are made in the ICU. Such decisions revolve around both treatment concerns and ethical issues. The type of treatments and interventions that are offered to patients inevitably vary with respect to a number of factors. Among those factors are the patient’s diagnosis and projected likelihood of recovery as well as the overarching issue of whether or not the patient has truly arrived at what can be considered the end of life or a point close to that.264

Although patients in ICUs do receive care for a variety of disease states, the leading causes of death in the ICU consist of multi-organ failure, cardiovascular failure, and sepsis. Multi-organ failure has a reported mortality rate between 11 and 18 percent while sepsis carries
with it a mortality rate of 25 to 30 percent. Of patients diagnosed with sepsis, as many as 51 percent will develop acute renal failure, 18 percent or more will experience acute respiratory failure, and more than 80 percent will experience myopathy or polyneuropathy.\textsuperscript{265}

Overall, the mortality rate of patients who have been admitted to an adult ICU ranges from 10 to 29 percent. In pediatric ICUs, the mortality rate associated with sepsis is 13.5 percent. Overall, the mortality rate for pediatric ICU patients ranges from two percent to six percent. As Machado points out, these data are indicative of the fact that the ICU is a place where ethical decisionmaking is a major concern.\textsuperscript{266}

In the United States, decisions regarding the type of treatment and intervention that should be administered to patients at the end of life stage require an understanding of a variety of factors. As is the case elsewhere culture plays a significant role in determining how family members and patients themselves will react to such decisions. Hester examined moral issues surrounding care for the dying using a radically empirical philosophy that draws upon the ideas of William James. Hester says that “value, itself, arises in experience, not imposed upon experience from some transcendent realm of value, and that the ‘dying process is part of living.’”\textsuperscript{267}

The kinds of decisions that are necessarily made in the ICU include a strong focus on whether or not cardiopulmonary resuscitation (CPR) should be offered to patients. Beliefs about whether or not CPR is appropriate vary in the United States with some physicians of the opinion that an intubated individual with a terminal condition should not unnecessarily or capriciously be subjected to CPR. Some family members, however, are of the belief that even heroic measures should be undertaken if a patient has not in fact signed an advanced directive or living will indicating his or her preference.\textsuperscript{268}
A do not resuscitate (DNR) order is often presented to individuals believed to be at risk for admission to the ICU. Of course, this presupposes that the patient prior to ICU admission is mentally competent to make this kind of decision. Often, the decision falls to the spouse, children, parents, or significant others who must make decisions on behalf of the patient – particularly in those instances when the patient does not have a living will or advanced directive that is accessible.269

Others have pointed out that among the decisions that must be made in the ICU are concerns regarding withdrawing life sustaining treatment and therapy. Ganzini, for example, made note of the fact that a substantial number of patients in the ICU experience a combination of conditions requiring disparate treatments and interventions such as the use of mechanical ventilation and the administration of pharmaceutical preparations that mitigate the effects of delirium.270 Withdrawing and withholding treatment are likely to be among the most challenging ethical decisions that are made in this setting.

Delirium is a common aspect of the status of patients in ICUs. Additionally, as Clark has pointed out, many patients approach the end of life from the perspective of a desire not to experience prolonged suffering or to cause undue emotional distress and financial cost for their families. Consequently, decisionmaking in the American ICU may incorporate support for the notion that an individual has the right to die.271 This does not lead inevitably to the conclusion that a physician will support a call for assisted suicide. Rather, it speaks to the possibility that a physician will accept a patient’s decision that treatment is not wanted or must be withdrawn. Here, again, one finds respect for patient autonomy to be a primary determinant of decisions that are made in the ICU as death is deemed inevitable and impending.
Several conclusions regarding the intensive care system in the United States can be offered. For example,

- This system focuses on the process of limiting unwanted and perhaps futile therapy among terminally ill patients at the end of life stage.\textsuperscript{272}
- Institutions and caregivers are legitimately concerned with cost containment, especially when resources are limited and there is no reason to assume that treatment will offer meaningful benefits.
- Patients and/or their families are actively encouraged in the U.S. health care system to create advanced directives and Do Not Resuscitate (DNR) orders to have guidance for physicians and other caregivers with respect to end of life treatment preferences.
- Informed Consent is a cornerstone of the U.S. system.
- The U.S. system further emphasizes the necessity of including family and significant others in making end of life decisions for patients who are unable due to the nature of their condition or status to communicate effectively with physicians.\textsuperscript{273}

It is in this general context, therefore, that decisions in the American ICU are positioned. Treatment decisions are also shaped by the doctrine and process of informed consent. Informed consent essentially involves ensuring that a patient and/or his/her family members or significant others are fully aware of the nature and likely effect of treatments and interventions. Obtaining an informed consent agreement prior to most surgical procedures is common in the United States and is regarded as a source of protection for caregivers, institutions, and patients alike. Informed consent is now a cornerstone of the American healthcare system.\textsuperscript{274}
Much the same process that governs the ICU can be said to govern hospice care. In essence, the system in the United States is based upon a growing sense that patients should possess autonomy and the right to make decisions on their own behalf when they are mentally competent to do so. Thus, the right to refuse treatment is deeply ingrained in the United States system.275

**ii. Principles Guiding the Decisionmaking Process**

While the foregoing section of this study might lead one to conclude that there is near universal agreement among healthcare providers, consumers, and policymakers in the United States regarding the ethical principles that should underpin and guide end of life decisionmaking, this not necessarily the case. Shugarman, et all have pointed out that not all U.S. hospitals adhere to a set of standards regarding DNR orders, informed consent, and so on.276 There is, therefore no single “national standard” or sets of guidelines on these contentious issues. One can claim with legitimacy that in the U.S., there is broad agreement on principles as relevant to end of life care, but not necessarily on practices in this context.

For individuals living with chronic disease who approach the end of life neither prevention nor cure is ordinarily possible. In this phase of life, healthcare must serve goals that go beyond prevention and cure and address goals such as pain, and symptom management; communication about diagnoses, prognoses, and alternative treatment plans; treatment decisionmaking consistent with patient and family preferences; support for addressing existential and spiritual concerns, and the completion of life tasks; the continuity and coordination of services; addressing the economic aspects of care; and support for families and caregivers.277

Generally, decisionmaking processes occurring in the ICUs in the United States tend to be undertaken in light of four fundamental principles of bioethics. These are respect for
autonomy and the right of individuals to make decisions on their own behalf, justice, non-maleficence, and beneficence. These principles are fairly broad and, one might suggest, somewhat generic. There is always the possibility that one interpretation of a principle may be at odds with another interpretation. As Luce and White suggest, the problem with presenting these four bioethical principles as adequate to guide all decisions concerning end of life care in the ICU or the hospice setting is inappropriate.278

Luce and White stated:

“The principles of beneficence and non-maleficence underlie the fiduciary relationship through which physicians serve the best interests of their patients and hold those interests in trust. Respect for autonomy allows patients to define and prioritize their interests. Justice situates patients within the larger society and acknowledges the importance of treating similar patients in similar ways.”279

One should note the term “fiduciary relationship” as it is employed in this statement. A fiduciary relationship includes financial obligations as well as ethical ones. Additionally, these analysts make the case that ethical principles alone may not be adequate when it comes to guiding all aspects of medical practice. What such principles do is offer physicians and other caregivers a broad framework for decision-making.

These four basic principles although enshrined within the medical system in the United States and regarded as fundamental in providing norms for the actions of physicians and other caregivers are not fully capable of generating unique solutions to the multitude of ethical issues that can and often do arrive in the end of life stage. It has also been noted that these four principles can conflict with one another. For example, it may be difficult to simultaneously act out of beneficence and non-maleficence when decisions about maintaining or withdrawing
treatment that reduces suffering at the cost of prolonging life beyond the wish of the patient to do so.\textsuperscript{280}

In discussing ethical issues at the end of life, Hester makes note of the fact that the normative goal of medical practice is to make it possible for individuals to live healthily. Further, the dying process is seen by Hester as representing a possibility for meaning which “arises as the marriage of our intelligently conceived ideals with the fortitude necessary to achieve them.”\textsuperscript{281} For Hester, meaningful lives as understood in the West include meaningful deaths that are created through ethical narratives that are authored by the dying individual and his or her community. In essence, Hester advances the idea that a good death is one in which a patient is allowed or assisted in the process of authoring the meaning of their own death and given the opportunity to determine what treatments they will and will not accept. (Parenthetically, one can note that the idea of a meaningful death is embedded in Islam as well, an issue that will be addressed later in this chapter).

Equally significant is Hester’s claim that in the United States, meaningful respect for patient autonomy ought to include both the option of passive euthanasia in the form of withholding life prolonging treatment as well as physician assisted suicide. Hester wrote that “for patients in these conditions, the choice to die and the ability to control the dying process can become a last act of significance, a way to end their stories on personal terms. They might wish to be progressive in their dying, transforming the abyss of death by giving meaning to the end of their lives.”\textsuperscript{282} Such an attitude is increasingly common among U.S. patients, who live in a societal environment in which individual rights sometimes are said to take precedence over other rights such as those of the collective.
However, despite Hester’s views (which have found support in many instances throughout the United States, especially with regard to “right to die” issues), the ethical concerns that tend to predominate in U.S. ICUs and other settings are not about the legitimacy or morality of physician-assisted suicide, but about when and how withdrawal of life-prolonging treatment should occur. Other issues include a focus on decision-makers as much as decisions; in other words, who makes the decision to terminate treatment? Hester references this issue with regard to the case of Ms. Terry Schiavo, a woman maintained on life-support whose husband and physicians argued in court that she was essentially brain dead; her parents claimed that she was somewhat aware and wanted her to be maintained on a feeding tube and other treatments. Ultimately, the husband was identified as the party who was responsible for making such a decision. This did not occur without a great deal of conflict playing out over a long period of time during which Ms. Schiavo continued to be maintained on life support systems.

The case illustrates the complexity of end-of-life decision, especially when withdrawing treatment is at issue. It also serves to demonstrate that while in general one can claim that such decisions are well understood ethically and procedurally in U.S. settings, conflict is still possible. Theoretically, Ms. Schiavo’s husband, Michael, had the legal authority to make decisions on her behalf. The courts found that her parents had at least standing to contest that right. Luce and White suggest that ensuring that institutional policies are clearly delineated, that patients and their significant others are made aware of those policies, that physicians respect the policies of the institution, and that a process is in place to facilitate end-of-life decision making are necessary. 285

The legal and regulatory environment in the United States also directly impacts upon end of life decisionmaking in the ICU and elsewhere. Informed consent, as noted above, is derived
from the concept of individual autonomy, which is a doctrine emphasizing the necessity of respecting an individual’s inherent right to make decisions about issues that impact upon their lives. In 1990, the U.S. Congress passed into law the Patient Self-Determination Act (PSDA) which affirmed the concept of autonomy and the practice of informed consent.286 A description and brief summary of the PDSA is as follows:

“Patient Self Determination Act of 1990 - Amends titles XVIII (Medicare) and XIX (Medicaid) of the Social Security Act to require hospitals, skilled nursing facilities, home health agencies, hospice programs, and health maintenance organizations to: (1) inform patients of their rights under State law to make decisions concerning their medical care; (2) periodically inquire as to whether a patient executed an advanced directive and document the patient's wishes regarding their medical care; (3) not discriminate against persons who have executed an advance directive; (4) ensure that legally valid advance directives and documented medical care wishes are implemented to the extent permitted by State law; and (5) provide educational programs for staff, patients, and the community on ethical issues concerning patient self-determination and advance directives.”

This seminal legislation encouraged physicians and institutions to become significantly more responsive to patient wishes with respect to such treatment options as resuscitation and withdrawal of feeding and ventilation tubes. The end result is that patient autonomy in the United States takes precedence over the principles of justice, non-maleficence, and beneficence.288 (This is a critical finding.).

Luce and White further described the doctrine of informed consent:

“The right of patients to consent to or refuse medical treatment has been contained for centuries within English and American common law. Common law also has held that
physicians have a number of professional duties to patients, including the duty to endeavor to be beneficent and to avoid harm.\textsuperscript{289}

Further, Luce and White note that prior to the 20\textsuperscript{th} century, British and American courts alike did not identify informed consent as a duty imposed on physicians except in cases when medical experts testified that such consent “comprised an ordinary and beneficial part of medical therapy.”\textsuperscript{290}

Luce and White also note that:

“The legal obligation of clinicians to obtain consent before treating patients was established by several landmark decisions in the US in the 20\textsuperscript{th} century. In the first case, \textit{Schloendorff v. Society of New York Hospitals}, the Court of Appeals of New York in 1914 determined that “Every being of adult years and sound mind has the right to determine what shall be done with his own body ---.”\textsuperscript{291}

In a second case, \textit{Salgo v. Leland Stanford University Board of Trustees}, heard in 1957, the California Court of Appeals stated that caregivers must inform a patient of all relevant facts pertaining to his or her condition that might impact upon rights and interests. In the third significant case, \textit{Cobbs v. Grant}, the California Supreme Court called for ensuring that a physician’s communication with a patient must be measured by the needs of the patient. What this means, in essence, is that the Court felt that information given to a patient regarding his or her condition must be in keeping with the needs of the patient. Thus, there are legal precedents that apply in the case of informed consent. One cannot overstate the significance of this particular normative principle in the U.S. ICU.
Patient autonomy emerges as a critical principle in determining how responses to patient concerns will be addressed during end of life decisionmaking processes. Other principles that are less centered upon patients than on resources are the principles of objectivity, prioritization, and efficiency. Even in the United States where there are a broad array of accessible medical care centers and where the government has taken steps to make healthcare affordable, there legitimate concerns regarding the viability of providing all ICU resources to all patients. Ravenscroft and Bell make note of the fact that ICU resources are limited and that decisions must be made as to which patients will receive which resources and the extent to which resources will be made available to an individual. Such principles impact said Ravenscroft and Bell on decisions centered on withdrawing or withholding treatment, futile treatment, and DNR orders.292

While much of the emphasis in end of life decisionmaking in the ICU is on the patient and his or her legitimate concerns, physicians and healthcare institutions working within the context of the ICU also have obligations with respect to resource utilization. They are challenged to ensure that the principle of justice is addressed. This means, in essence, that it is necessary to allocate resources in such a way that they will not be consumed, as it were, largely or exclusively one particular group to the detriment of another. Left to themselves, were there no constraints on behavior, it seems like that powerful and more affluent individuals would claim and acquire more of the limited resources that are available.293

Thus, it is incumbent in the U.S. ICU professionals to make difficult decisions regarding the distribution of ICU resources. Efficiency matters as does cost containment in an era when the costs of medical care are escalating drastically. Generally, the emphasis in the ICU is placed on making sure that interventions are targeted to patients who are likely to survive and whose survival depends upon accessing such resources. Siegel asserts that giving priority to patients
with the best chance of genuinely benefitting from an ICU intervention is a way of ensuring that resources are used effectively while also adhering to the principles of justice and beneficence.  

Another principle of increasing significance in the United States intensive care system is prognostication. Essentially, the principle of prognostication is a derivative of the recognition that a patient’s preferences can be seen as evolving in tandem with or response to their medical condition. What this means is that as a medical condition unfolds, a patient may change his or her mind about the kind of treatment that he or she is willing to undergo. A person whose general prognosis is reasonably good may choose to remove a DNR order from their medical records to prevent it from being exercised in the event of a cardiac which could be overcome through intervention.

The intensive care system in the United States has become focused on the use of prognostic scoring systems that assist physicians in making more accurate prognostications about their patients’ likely medical and health trajectory. A patient informed that death is imminent will clearly react differently to the notion of a futile intervention than a patient informed that with treatment a reasonable quality of life for an indefinite future is possible. These tools cannot predict patient response or reaction to the verdict that a condition is inescapably permanent and terminal.

One prognostic scoring system that has gained popularity in the United States is the Acute Physiology and Chronic Health Evaluation (APACHE) that assists physicians in making decisions about patient care. APACHE is described as follows:

“The APACHE II score is made of 12 physiological variables and 2 disease-related variables. Within the study period, 87% of all ICU patients had all 12 physiologic measurements available. The worst physiological variables were collected within the first
24 hours of ICU admission. The "worst" measurement was defined as the measure that correlated to the highest number of points. The study did not continually calculate an APACHE II scores beyond the first 24 hours of ICU admission. The APACHE II score ranges from 0 to 71 points; however, it is rare for any patient to accumulate more than 55 points.  

In their discussion of prognostication, Luce and White state that what patients want in terms of attempts at life prolongation varies according to the information about their prognosis that they are being given by physicians. In the United States, “some prognostic information has been derived from ICU studies of patients with specific disorders such as chronic obstructive pulmonary disease (COPD) and Pneumocystis pneumonia and the acquired immune deficiency syndrome (AIDS), and the acute respiratory distress syndrome.”

Other information has been obtained not only through systems such as APACHE but also from studies of age groups such as the elderly or interventions such as mechanical ventilation. Prognostic scoring systems like APACHE are limited in that physicians do not necessarily or consistently use information they provide any more than they are likely to rely on advanced directives. There appears to be substantial variation in how such tools are used by American physicians.

Luce and White state that a longitudinal study involving a large cohort of hospitalized adult patients with such conditions as advanced COPD demonstrated that when APACHE or a similar prognostic scoring system was used, prognoses were not uniformly reported to patients based on test results. In fact, physicians often used their own knowledge of patients’ preferences regarding resuscitation and data such as the number of days spent in an ICU receiving mechanical ventilation or in a comatose state to generate a prognosis.
Another principle that is used in the ICU for medical decisionmaking is the concept of futility as it relates to the aforementioned allocation of medical resources. Luce and White state that reducing “resource use or allocating medical resources to patients most likely to benefit from them has been a concern – if not an agenda item – in ICUs almost since their inception.”\(^{299}\) The concept of medical futility has long been used to rationalize unilateral decisionmaking by physicians. Futility is quantitatively defined as a medical intervention that has not been found to be useful in the last 100 cases; it is qualitatively defined as interventions that only preserve permanent unconsciousness or dependence on intensive medical care.\(^{300}\)

The problem with futility was identified by Luce and White as follows:

“Outside the rare circumstances of strict physiological futility, it is a value-laden concept about which a consensus has not been achieved. Moreover, physicians sometimes invoke futility to hide what are really implicit resource allocation decisions that should be discussed explicitly. These problems were acknowledged in 1997 by the SCCM, which argued that “Treatments should be defined as futile only when they will not accomplish their intended (physiologic) goal. Treatments that are extremely unlikely to be beneficial, are extremely costly, or are of uncertain benefit may be considered inappropriate and hence inadvisable, but should not be labeled futile.”\(^{301}\)

The American Medical Association (AMA) has expressed the consensus of its membership on end-of-life care and the role of physicians in a series of formal opinions. Those that are relevant herein are:
Table 1

AMA Opinions on End-of-Life Care

**Opinion E-2.035 Futile Care**
Physicians are not ethically obligated to deliver care that, in their best professional judgment, will not have a reasonable chance of benefiting their patients.

**Opinion E-2.037 Medical Futility in End-of-Life Care**
When further intervention to prolong the life of a patient becomes futile, physicians have an obligation to shift the intent of care toward comfort and closure.

**Opinion E-2.17 Quality of Life**
In the making of decisions for the treatment of seriously disabled newborns or of other persons who are severely disabled by injury or illness, the primary consideration should be what is best for the individual patient.

**Opinion E-2.20 Withholding or Withdrawing Life-Sustaining Medical Treatment**
The social commitment of the physician is to sustain life and relieve suffering. Where the performance of one duty conflicts with the other, the preferences of the patient should prevail.

**Opinion E-2.21 Euthanasia**
Euthanasia is the administration of a lethal agent by another person to a patient for the purpose of relieving the patient's intolerable and incurable suffering.

**Opinion E-2.211 Physician-Assisted Suicide**
Physician-assisted suicide occurs when a physician facilitates a patient's death by providing the necessary means and/or information to enable the patient to perform the life-ending act.

**Opinion E-2.22 Do-Not-Resuscitate Orders**
Efforts should be made to resuscitate patients who suffer cardiac or respiratory arrest except when circumstances indicate that cardiopulmonary resuscitation (CPR) would be inappropriate or not in accord with the desires or best interests of the patient.

**Opinion E-2.225 Optimal Use of Orders Not To Intervene and Advance Directives**
More rigorous efforts in advance care planning are required in order to tailor end-of-life care to the preferences of patients so that they can experience a satisfactory last chapter in their lives.

**Opinion E-8.081 Surrogate Decision Making**
The following guidelines offer a process for determining who the decision maker should be for an individual who lacks decision-making capacity. They outline steps the designated decision maker should follow in making health care determinations on behalf of the patient. They identify resources for health care professionals and/or families in case of decision-making conflict.302
These formal statements are meant to be normative across provider institutions. They are considered to be relatively binding on physicians.

It is also important in the context of principles used in American ICUs to shape and guide end of life treatment to understand the role played by culture in general and culture in particular. Clarfield, Gordon, Markwell, and Alibhai, who compared ethical issues in end of life care in three monotheistic religions (Judaism, Catholicism, and Islam) made reference to the fact that Catholicism as one example of Christianity provides a bioethical system holding that faith, human reason, and individual conscience should work together to interpret Scripture. 303

While the United States is culturally diverse and is home to many different religious and faith communities, it would not be inappropriate to argue that the Judeo-Christian ethical traditions are dominant in this country. Consequently, medical care ethics in the United States reflect a strong belief in the value of human life as well as the necessity of ensuring that attention is given to issues of justice, equity, spirituality, and the elimination of medical paternalism. 304 Most Christians appear to acknowledge and advocate for patient empowerment, along with a holistic view of health which recognizes the emotional, spiritual, and self-awareness along with the needs of patients. 305

Culturally, most Americans are likely to argue for the necessity of acknowledging the role played by medical bioethics and the religious belief and value systems of patients. 306 Consequently, there is likely to be disagreement among patients, practitioners, and healthcare institutions on the question of what constitutes genuine futility with respect to the delivery of treatment. Because this is the case, many physicians now tend to focus on avoiding paternalism and providing support for families and patients as they go about the task of making critical decisions that impact on the life of the individual.
Finally, one should note that while the United States via the activities of organizations such as the AMA has worked to create an ethical and normative framework that can be used universally to guide end of life decisionmaking, it is by no means possible to argue that such decisions are all undertaken within this framework. As described by Beca and Astete, decisions regarding the prolongation of life, the withdrawing or withholding of treatment, and the allocation of resources are emotionally charged and intensely personal decisions. Physicians play a vital role in facilitating such decisions, but they are not and according to U.S. ethical standards should not be the sole voice in such decisions.

The United States is by no means a homogeneous society. It is culturally diverse in every imaginable way. Consequently, while there are very real guidelines, regulations, codes, laws, and policies which together shape decisionmaking at the end of life, one must expect and account for somewhat extensive variance across the country. One can conclude that culture matters and that it influences such decisions. There are, for example, some seminal differences to be observed in the bioethical orientation of medical institutions that are owned and operated by religious groups and those that are secular.

Nevertheless, incorporating many of the elements that were identified above as integral to medical decisionmaking during the end of life stage into practices in the Kingdom of Saudi Arabia may very well be both desirable and useful. The next section of this chapter will explore the processes by means of which such decisions are made in Saudi Arabia and the ethical principles that shape these decisions.

B. Saudi Arabia

According to Al-Omari, Abdelwahad, and Alsanari, the Kingdom of Saudi Arabia (KSA), is one of the largest Middle Eastern countries: it has a landmass of 2.5 million square
kilometers, and has transformed over 50 years into the most urbanized country in the region. With an estimated population of almost 30 million residents and an annual growth rate of 2.7%, the Saudi Arabian healthcare sector is designed to respond to the needs of a rapidly growing population, which is placing enormous demand on the healthcare sector for new and high quality services.\textsuperscript{308}

With this in mind, one would anticipate that intensive care medical services, along with related end-of-life and/or critical care interventions, would receive significant attention from leadership in the Saudi medical establishment as well as from the religious establishment of the nation. This is, in fact, the case, but it is important to acknowledge that are such issues are framed within the Saudi context in terms of Islam, as has been discussed elsewhere in this study.

Al-Omari, et al, further point out that there is an increasing demand for critical care services in KSA; globally, this demand is attributable to the increasing population age, longer survival of previously incurable diseases, and advanced surgical procedure that makes post-operative intensive care admission mandatory.\textsuperscript{309} Previously, most patients requiring highly specialized care sought care abroad. Today, with significant advances occurring in the Saudi healthcare system, particularly in the realm of critical care medical services, it is not necessarily the case. Further, many highly qualified physicians and surgeons are returning to the Kingdom after completion of their postgraduate training in international academic medical centers; this has led to the introduction of new treatment modalities, such as bone marrow and liver transplantation and radical cancer surgeries. Such therapies and surgeries typically require intensive care. Factors like worldwide growth in the critical care specialty and the national introduction of advanced medical therapies were other reasons behind the recently witnessed major developments in critical care medicine in KSA.
Presented below is a table illustrating the different levels of critical care currently available in Saudi hospitals.

**Table 2**

**Different Level of Critical Care in Saudi Arabia Hospitals**

<table>
<thead>
<tr>
<th>Critical care level</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td>Primary hospitals (n=2037)</td>
<td>• Small ICUs with limited equipment</td>
</tr>
<tr>
<td></td>
<td>• Staff with no or little ICU training</td>
</tr>
<tr>
<td></td>
<td>• Found in remote areas and villages</td>
</tr>
<tr>
<td>Secondary hospitals (n=244)</td>
<td>• Larger and better-equipped ICUs</td>
</tr>
<tr>
<td></td>
<td>• Open ICUs with intensivist coverage</td>
</tr>
<tr>
<td></td>
<td>• Found in small cities</td>
</tr>
<tr>
<td>Tertiary hospitals (n=56)</td>
<td>• Well-equipped specialized ICUs</td>
</tr>
<tr>
<td></td>
<td>• Nurse: patient ratios of 1:1</td>
</tr>
<tr>
<td></td>
<td>• Most are closed ICUs covered by on-site</td>
</tr>
<tr>
<td></td>
<td>certified intensivists 24 hours a day, 7</td>
</tr>
<tr>
<td></td>
<td>days a week</td>
</tr>
</tbody>
</table>

*The numbers indicate the number of hospitals found in Saudi Arabia. ICU- intensive care unit

As these data demonstrate, the availability of ICU care for the critically ill patient in the Kingdom varies quite substantially when one takes into account the differences between the more common primary hospitals and the less accessible tertiary hospitals. Nevertheless, as Al-Omari, et al indicate, cases needing more complex levels of care in the Kingdom are transferred to specialized hospitals.311

That said, it is important to acknowledge that critical care medicine in Saudi Arabia has undergone a number of important transformations in recent decades as increased investment in the medical sector have been forthcoming from the government.312 Part of the reason for this
increased attention to ICU care in the Kingdom is due to the fact that during the *haj* – the period during which millions of Muslim pilgrims arrive in the Kingdom to worship in Mecca and Medina – the Saudi hospital system experiences some significant stresses. The influx of men, women, and children into the Kingdom brings about a situation in which medical services are subjected to increased demands as individuals experience such crises and traumas as unanticipated heart failure, accidents leading to life threatening injuries, and other forms of collapse requiring ICU care.

While the *haj* is an important impetus for improving critical care services in the Kingdom, it is certainly not the only explanation for this movement. Al Omari, et al noted that the Saudi Critical Care Society (SCCS) is “a premier critical care society in the Middle East with its largest and most expansive education programs focused on serving the critical care community in KSA (both adult and neonatal).” The SCCS assists in developing the critical care sector and disseminates quality information and knowledge among its membership. It has a long and quite distinguished history of staffing Saudi critical care units during the *haj* as well as “training staff at MOH hospitals and training generation after generation of critical care managers through association with the Saudi Healthcare Leadership Institute.”

Riyadh is a center of many different activities in the Kingdom and is particularly a focus of tertiary care medical programming. Presented below is Table 3 depicting the number of Riyadh hospital ICU beds.

**Table 3**

The number of Riyadh hospital ICU beds, intensivist, and nurses.
These data do support the argument that more attention is being given by the Ministry of Health to providing sufficient ICU services to a population that swells annually due to an event that is of enormous significance not only to the Kingdom but also to the entire Muslim international community. As Al Omari, et al put it: “Planned annual large gatherings and events pose a huge logistic challenge in providing medical care, especially critical care…. Within the immediate vicinity of the Hajj, there are more than 130 centers equipped with the latest emergency management medical system.”

Research supports the argument that the *haj* is a major driving factor in expanding and enhancing the Saudi ICU system. Mandourah, Ocheltree, Al Radi, and Fowler conducted a prospective cohort study of the critically ill patients during the 2009 pilgrimage, finding that 110 patients needed to be admitted to ICUs for a variety of reasons. These patients had a mean Acute Physiology, and Chronic Health Evaluation IV score (APACHE IV) of 60.5. Sixty patients or 54.6 percent required ventilation upon admission. Their median predicted mortality by APACHE IV was 14 percent. However, this study revealed that because the Kingdom was able to provide a state of the art full service ICU, the short-term mortality (i.e., over two weeks) was only 6.4 percent ($p = 0.009$).
The Ministry of Health in the Kingdom of Saudi Arabia has invested substantially in a variety of different health activities. In 2012, the cumulative budget allocation for all Ministry of Health activities was about 54 billion Saudi Riyals, up from 25 billion Saudi Riyals in 2008. The strategy of the Ministry placed “particular emphasis on expanding the critical care services and promoted the accessibility and feasibility of the critical care services… establishing and developing new general hospitals, medical cities, and specialist hospitals.”

It is certainly worth pointing out that under the Saudi health care system, the delivery of critical care services to all Saudi citizens and to expatriates working in public sector roles is free of charge to all. Most Saudi ICUs are government owned. They tend to be characterized by a multicultural environment due to the fact that a significant number of healthcare professionals are individuals who have in fact been recruited from other countries. Much of this occurs under the aegis of assistance from the Ministry of Health as well as the SCCS which serves in an advisory capacity to individual hospitals as well as the Ministry of Health itself.

In light of the concerns regarding the expansion of ICU services in Saudi Arabia, some researchers have observed a slowly but steadily developing set of research activities. Almalki, Fitzgerald, and Clark for example, noted that there are relatively few comprehensive medical and other databases presently available in most Saudi Arabian ICUs. Inadequate statistics, limited training in research, and an emphasis in funding on services rather than research contribute to this particular problem.

A survey conducted by Al Dorzi, Naidu, Khokhar, White, and Arabi sought to identify barriers to participation in ICU related research in the Saudi Arabian medical sector. The study indicated that ICU staff believed that research was overly challenging due to lack of time, lack of financial compensation, and lack of encouragement. In addition, this study also revealed that
ICU staff in Saudi Arabia may perceive the inherent challenges of their work to be so overwhelming that participation in scientifically sound and rigorous research may be impossible or at least overly time consuming.

In the opinion of Al-Omari, et al, “critical care service in KSA has the elements needed for success through its leadership support and manpower. In fact, the performance of many tertiary ICUs scattered throughout the Kingdom parallels that of many similar units in industrialized countries.” That said, it is necessary to point out that decisionmaking in Saudi Arabian ICUs is very different than it is in the United States and other Western countries.

i. **Decisionmaking in Saudi ICUs**

Earlier in this study reference was made to the fact that in Saudi medical practice, there is a longstanding tradition of employing a paternalistic model of physician centered decisionmaking. In Western countries, a patient centered model is infinitely more commonplace. Arabi and Al Shimemeri note that in Saudi Arabia, physicians tend to make decisions on behalf of individuals with some participation from adult male family members rather than via direct interaction with patients themselves.

In many instances, this emphasis on paternalistic physician decisionmaking leads to treatments or interventions that may be contrary to the wishes of patients or the withholding of treatments that patients may wish to receive. Research by Al-Jahdali, Baharoon, Al Sayyari, and Al-Ahmad focused on an analysis of the extent to which advanced medical directives are employed in Islamic medical institutions, noting that such directives are specific competent consumers’ wishes about future medical plans in the event that they become incompetent. Awareness of the autonomy of patients, according to these researchers, is a characteristic of Islamic medical practice but the use of advanced directives is very limited in Muslim societies.
This is despite the fact that Islam and Muslims in general have an excellent understanding of death and dying and Islam allows the withholding or withdrawal of treatment in cases wherein intervention is considered to be futile.

Al-Jahdali, et al pointed out that living wills in Saud Arabia have no formal recognition or status with respect to decisionmaking regarding end of life care. While many individual patients may choose to create such instruments and make them available to other family members and/or physicians, these instruments themselves have no protected legal status in the Kingdom. Wills that are provided with protected status in Saudi Arabia are those instruments that become valid after the individual dies and their contents are only applicable to property issues. Many Saudi physicians do not discuss advanced directive or advanced care planning with patients.

The common do not resuscitate or the DNR orders that are found in Western countries can only be given by physicians in Saudi Arabia. DNR is a new concept in Saudi Arabia and King Fahad National Guard Hospital has been a leader in raising awareness in the Kingdom regarding the futility of aggressive life support in terminally ill patients. A study by Rahman, et al reviewed records of all adult patients at King Fahad National Guard Hospital who died in 1998, reviewing and evaluating patients’ demographics, underlying chronic illnesses, admission diagnosis, length of stay, the timing of writing DNRs, and whether or not death occurred in a ward or an ICU. Results revealed that DNR orders were written for 318 out of 420 deaths (76 percent).

Rahman, et al reported further that one-third or 34 percent of all deaths accounted for in their study occurred in the ICU where DNR orders were written for 66 percent of all deaths in comparison to 82 percent of ward deaths. The study also revealed that the majority of patients
identified as in imminent danger of dying were given DNR orders by their physicians at the time they died. Dying patients with cancer, cirrhosis, and those admitted with sepsis were less likely to be resuscitated whereas dying cardiac and trauma patients were more likely to continue receiving full support. Interestingly, the research revealed that DNR status tends to be initiated early in cancer patients which reflects an awareness of the limited value of aggressive life support in this group of patients.328

The law is very clear in that at least three trustworthy and knowledgeable physicians must agree that a patient’s condition is irreversible in order for a DNR to be approved. This No Code policy does not empower families and patients to participate in decisionmaking. Instead, in keeping with the overtly paternalistic approach that is found in Saudi Arabian medical institutions, these individuals are only informed about a DNR decision or a decision to terminate treatment because it is believed that as nonprofessionals, they are not qualified to make such decisions.329

The No Code policy is described as follows:

“The Islamic religions concepts concerning DNR decision have been clarified by the Presidency of the Administration of Islamic Research and Ifta, Riyadh, KSA, in their Fatwa No. 12086 issued on 30.6.1409(Hijra) [1988 (AD)]. The Fatwa states that: “if three knowledgeable and trustworthy physicians agreed that the patient condition is hopeless; the life-supporting machines can be withheld or withdrawn. The family members' opinion is not included in decision making as they are unqualified to make such decisions”. 330

Based on the above Fatwa,
“Many hospitals in Saudi Arabia have implemented a “No Code” policy. The policy states that: (“No Code” status is applied after agreement of three physicians, two of whom at least are consultants. The family members will be informed about the decision. In case of conflict with the family, arrangements to transfer care to another facility may be made. The policy had led to a dramatic reduction in futile CPR. In fact, DNR orders are written currently for 66% of patients who die in ICU and 82% of patients who die in the wards. However, there is still a great variability in DNR practices. For example, DNR orders are more likely to be written on day one of hospitalization in cancer patients and on the last hospital day in cirrhotic patients, underscoring the delays in recognizing the futility of the treatment in some patients.”

Invariably, there are instances in which families will not agree with the decision of physicians. In such cases, it is commonplace to permit a family to transfer a patient to another facility. This does not mean, however, that a family will be more satisfied in a different medical institution. Generally, Rahman notes that when decisions are made by a team of three physicians regarding withholding or continuing care, a second group of physicians is unlikely to change this initial decision.

**ii. Practices in Saudi Arabian ICUs**

Al Husseini, in an academic thesis focused on the implications of religious beliefs on medical and patient care, pointed out that in Saudi Arabia, paternalism is a key characteristic of the relationship between physicians and patients on the one hand and physicians and patients’ relatives on the other. This is due to several reasons, among which one must include a sense that disclosing bad news can be inhumane, disrespectful, and unethical. Al Husseini notes that the
reluctance of Saudi physicians to engage patients and their families in a discussion of end of life care undercuts the autonomy of patients.\textsuperscript{334}

Additionally, research by Aljubran indicates that disclosing the diagnosis or prognosis to terminally ill cancer and other patients is seen by physicians as inherently challenging. The public attitude observed in the Kingdom toward full disclosure is still conservative. Governing the public attitude according to this analyst is a conviction that death is merely another element in life that must be understood and respected but not an element which must be discussed at great length.\textsuperscript{335} At the same time, there is a firm conviction on the part of physicians that it is not necessarily appropriate to disclose such information in many if not all cases.

Arabi and Al Shimemerri conducted a research effort in which physicians practicing in six hospitals throughout Saudi Arabia were asked to describe their practices with respect to providing patients and their families with information regarding a poor prognosis and anticipation of the need to end treatment. This research indicated that fewer than 50 percent of Saudi physicians working in ICUs furnish patients and their families with comprehensive information regarding life threatening illnesses. Among the reasons for failing to disclose were such items as a belief that patients and families lacked the knowledge to fully comprehend the situation and a sense that disclosing such information would cause more anxiety than was acceptable.\textsuperscript{336}

Arabi and Al Shimemerri also make note of the fact that the Saudi intensive care system has given only limited attention to questions regarding principles of prioritization and objectivity. There is a limited understanding of the necessity of prioritizing resource allocation and using evidence based practices to ensure that resources are allocated among patients who are likely to benefit from such services. These issues are reflected in the fact that there is limited
knowledge among physicians and laypeople regarding evidence based decisionmaking in the ICU.337

In a study of knowledge regarding DNR orders, Aljohaney and Bawazir sought to analyze the perceptions and perspectives of internal medicine residents in the western region of Saudi Arabia regarding the implementation of DNR orders. The goal was to develop sufficient understanding of educational deficiencies to improve future training practices among physicians. Medical residents in Jeddah, Mecca, Medina, and Taif were invited to participate in a cross-sectional survey regarding DNR orders in which a 16-item survey was distributed and analyzed.338

Of a potential sample of 364 residents, 157 or 43 percent completed the questionnaire. Results showed that most or 66 percent of internal medicine residents in the target area did not engage in DNR discussions with patients and family or surrogate decisionmakers. Nevertheless, about one-half or 51.9 percent reported that they were comfortable with such conversations but were convinced that additional educational programs were needed in order to ensure that physicians would be more comfortable in addressing issues related to DNR discussions.339

The attitude of many Saudi physicians is certainly influenced by Islamic teaching on physician assisted suicide and both voluntary and non-voluntary euthanasia. Van den Branden and Broeckaert undertook an examination of English Sunni e-fatwas that provide Muslims worldwide with a form of Islamic normative guidance on a variety of topics including end of life issues.340 These researchers analyzed 32 English Sunni e-fatwas that were focused on (non) voluntary euthanasia and assisted suicide. Each of the individual e-fatwas discussed by the authors speak firmly against every form of active termination of life.
According to Van den Branden and Broeckaert, these texts often bear the same structure, being based solely on verses from the Qur’an and prophetic traditions rather than classical jurisprudence on the subject. With respect to content, these texts comprise an influential and important developing body of Islamic orthodox normative authority on end of life ethics. The subject is, however, still very much in the process of being examined with respect to overall Islamic ethical positions impacting on the delivery of medical care. It would appear that practice is still evolving in the Kingdom in this area.

The relevant Islamic law issues involved in end-of-life decisions and DNR were analyzed by Kasule, who generated the following data.

Table 3

<table>
<thead>
<tr>
<th>Ethical Issues in ‘Do Not Resuscitate’ (DNR) and maqasid al shari’at.</th>
<th>Purpose</th>
<th>Ethical issues and practices</th>
</tr>
</thead>
<tbody>
<tr>
<td>Protection of life, <em>hifdh al nafs</em></td>
<td>Instituting beneficial artificial life support protects life</td>
<td>Euthanasia in the form of a DNR order violates life</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Instituting futile life support wastes resources</td>
</tr>
<tr>
<td>Protection of wealth, <em>hifdh al maal</em></td>
<td>Inappropriate ICU admission wastes resources</td>
<td>Over-utilization of ICU resources for futile cases</td>
</tr>
<tr>
<td></td>
<td>Resource conservation by palliative care in ICU</td>
<td></td>
</tr>
</tbody>
</table>

Table 4

<table>
<thead>
<tr>
<th>Ethical Issues in ‘Do Not Resuscitate’ (DNR) and qawa’id al fiqh.</th>
<th>Principle</th>
<th>Ethical Issues and Practices</th>
</tr>
</thead>
<tbody>
<tr>
<td>Principle of intention, <em>qa’idat al qasd</em></td>
<td>Difference between DNR and euthanasia is based on underlying intention</td>
<td></td>
</tr>
<tr>
<td>Principle</td>
<td>Ethical Issues and Practices</td>
<td></td>
</tr>
<tr>
<td>-----------</td>
<td>-----------------------------</td>
<td></td>
</tr>
<tr>
<td>Principle of certainty, <em>qa'idat al yaqiin</em></td>
<td>Definition of terminal illness involves uncertainty</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Determination of death involves uncertainty</td>
<td></td>
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<tr>
<td></td>
<td>Doubts about implementing pre-hospital DNR orders</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Confusing DNR for DNT</td>
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</tr>
<tr>
<td></td>
<td>Harm of intervention in futile cases with no foreseeable benefits</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Patient and family consent to DNR protects patients from harm,</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Violation of patient autonomy in DNR and CPR hurts patients’ interests.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Physician paternalism violates patients’ autonomy and safety.</td>
<td></td>
</tr>
<tr>
<td>Principle of injury, <em>qa'idat al dharar</em></td>
<td>Family assent to DNR is additional protection for the patient.</td>
<td></td>
</tr>
<tr>
<td></td>
<td>Age discrimination occurs when DNR orders are made for the elderly.</td>
<td></td>
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<tr>
<td></td>
<td>Respecting physicians’ conscientious objection to DNR</td>
<td></td>
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<tr>
<td></td>
<td>Regular audits of DNR decisions</td>
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<tr>
<td></td>
<td>Empirical research on DNR</td>
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<tr>
<td></td>
<td>Following policies and guidelines on DNR</td>
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<tr>
<td></td>
<td>Improving physician knowledge and practices regarding DNR</td>
<td></td>
</tr>
<tr>
<td>Principle of custom, <em>qa'idat al 'aadat</em></td>
<td>Procedures for correct identification of DNR patients</td>
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<tr>
<td></td>
<td>Criteria for selecting patients appropriate for DNR orders</td>
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<tr>
<td></td>
<td>Determining the content of a DNR order</td>
<td></td>
</tr>
</tbody>
</table>
Kasule stated that:

“The requirement for consent for DNR prevents harm to the patient according to the principal of dharar (Majallat Article No. 19). The patient or his or her family makes the crucial decision about DNR. DNR and advance directives assure the patient of prospective autonomy. The consent of the patient is the most effective way of fulfilling the purpose of protecting life, because the patient has an inherent interest in life and would not under normal circumstances seek self-harm” 343

The factors influencing a patient’s choice of a DNR – or the decision not to implement such an order – is based on such variables as perceived quality of life, perceptions of the nature of the prognosis they have been given, and understanding of hospice care. Some patients personally give consent for a DNR, while others rely upon family to take care of this issue on their behalf. These researchers indicated that poor physical or psychological condition, consultant concerns and family wishes were given as reasons for not involving some patients in discussing DNR. Thus, in Saudi Arabian health care institutions, ideally the patient would be making the DNR decision; however, this is not necessarily the case, as the system itself remains extremely paternalistic and this affects such decisions.

As Kasule put it: “Paternalism, an attitude whereby physicians consider that they know what is best for the patient and therefore make decisions without respecting the patient’s autonomy, can harm the patient’s interests and thus violate the principle of preventing harm or injury. In many cases, physicians act in the best interests of the patient, but there may be situations of conflict of interests that cloud their decisions.”344 Kasule concluded that what is lacking – and what is needed – in the Saudi healthcare system is a more thoroughly developed systematic approach to a nationwide DNR policy that eliminates some (if not all) of the
paternalism inherent in the philosophical underpinnings of the system. Such a policy would include education of physicians while they are in school or residency positions, and the development of institutional policies on DNR and living wills that are in keeping with Islamic law and culture. Such a task is, admittedly, challenging at best.

C. Incorporating Elements of the US ICU System in Saudi Arabia System

The Society of Critical Care Medicine (SCCM) in the United States reported that in the United States there are more than 5 million patients admitted each year to the ICU, with the five primary diagnoses associated with such admissions in decreasing order consisting of respiratory insufficiency/failure, postoperative management, ischemic heart disorder, sepsis, and heart failure.\(^345\) Since 1991, there has been a significant increase in the incidence of a number of serious conditions requiring ICU services (e.g., gastrointestinal hemorrhage, hemodynamic abnormalities, multiple organ system failure, respiratory insufficiency or failure, sepsis, and shock) – attributable to a degree to the fact that the US population is aging. SCCM stated that:

“Also evident is the dramatic rise in patients 85 years and older, from 4.1% in 1991 to 6.9% in 2004. Between 2000 and 2020, the population younger than 65 years is expected to grow by about 10%, while the number of individuals 65 years and older is projected to rise by approximately 50%.”\(^346\)

Further, SCCM reported that:

“Frequently, patients in the ICU require ventilatory or cardiovascular support, invasive monitoring, and intensive observation by nursing and physician staff members. With a greater reliance on technology to keep critically ill patients alive (i.e., mechanical ventilation, hemodialysis, plasmapheresis, extracorporeal membrane oxygenation), the
The number of ICU beds has grown dramatically in the United States, with the current estimate being >6,000. In 2000, children and adolescents accounted for 6.3 million hospital stays (18%).

The problem, therefore, impacts upon all age cohorts.

Living wills and advance directives regarding care – as well as DNR orders – are commonplace elements within the U.S. healthcare system. Fagerlin, Ditto, Hawkins, Schneider and Smucker conducted a review of relevant literature focused on issues related to the use of advance directives or living wills, a tool used to ensure that end-of-life decisions for an individual reflect that individual’s desires and wishes. They found that this crucial method of ensuring the autonomy of seriously ill patients is widely used but often poorly understood. Central to a successful living will are such assumptions as: people must complete them themselves; treatment preferences in living wills must be authentic; and surrogate decision-makers must be able to correctly interpret will content and use that content to make decisions on behalf of another. Like informed consent, however, living wills must be made by individuals competent to do so; the problem emerges when no will exists and surrogates are required to make care decisions based on their beliefs as to what others would want, given the circumstances. For caregivers, there are legal as well as ethical issues involved.

Thus, the U.S. healthcare system emphasizes the use of a variety of tools that facilitate end-of-life decision making while also emphasizing principles of patient autonomy. The strong emphasis placed on respecting the right of patients (and/or their competent caregivers) to make decisions regarding withdrawing or withholding treatment as death approaches or when it is clear that further intervention will not change a prognosis but only prolong life is a key characteristic of the U.S. system. The patient is perceived as the foremost “expert” with respect to such
decisions; the paternalism of the Saudi Arabia healthcare sector has given way in the United States and other Western countries to conviction that physicians act ideally in an advisory role in such case. Decisions regarding DNR and other related matters are left to patients and their families. Such a shift would be desirable within the Saudi system.

Using the Cruzan case as an example, Fagelin, et al (2002) note that the assumptions identified as critical to the authenticity of a living will may be too simplistically stated. The psychological state of the individual making the will – or the surrogate interpreting the unwritten or written wishes of another – must be taken into consideration. Public policy, they argue, moved ahead of the science – failing to include the input of psychologists who can assist in ensuring that an advance directive addresses all issues properly.350 Certainly, Saudi physicians would be concerned with these issues.

It is important to recognize that in the United States, the Code of Federal Regulations (CFR) also acknowledges the legal status of living wills, DNRs, and other similar instruments:

“Sec. 489.102 Requirements for providers.

(a) Hospitals, critical access hospitals, skilled nursing facilities, nursing facilities, home health agencies, providers of home health care (and for Medicaid purposes, providers of personal care services), and hospices must maintain written policies and procedures concerning advance directives with respect to all adult individuals receiving medical care by or through the provider and are required to:

(1) Provide written information to such individuals concerning--
(i) An individual's rights under State law (whether statutory or recognized by the courts of the State) to make decisions concerning such medical care, including the right to accept or refuse medical or surgical treatment and the right to formulate, at the individual's option, advance directives.\textsuperscript{351}

Other relevant CFR provisions state that “If an adult individual is incapacitated at the time of admission or at the start of care and is unable to receive information (due to the incapacitating conditions or a mental disorder) or articulate whether or not he or she has executed an advance directive, then the provider may give advance directive information to the individual's family or surrogate.”\textsuperscript{352} In essence, the rights of patients to participate directly in end-of-life decisions are affirmed in U.S. law – providing clear direction to caregivers and healthcare institutions as to the rights of patients and the responsibilities of healthcare institutions. Such a definitive statement of policy, while perhaps difficult in light of Islamic law and tradition, would be valuable in Saudi Arabia.

Arabi and Al-Shimemeri make note of the fact that one of the characteristics of the U.S. system that is to a large extent lacking in the Kingdom centers on the communicative interaction between medical caregivers and patients and their families.\textsuperscript{353} This is a reflection of the paternalism inherent in relations between Saudi physicians and their patients. Reducing, if not entirely eliminating, this attitude and its artifacts would be valuable in terms of creating a foundation for a more open and beneficial approach to end-of-life decision-making.

It is also necessary to acknowledge the importance of more directly educating patients and their families about end-of-life matters and the choices that are available. Van den Branden
and Broeckaert make note of the fact that educated, informed patients can be effective participants in all kinds of medical decisions and can assist physicians in determining appropriate interventions. Patient education has become a major focus in the U.S. healthcare system in recent decades as consumer advocates have challenged what was once a paternalistic system. Goodman, Froggatt, and Mathie argue that educated patients are likely to be more cooperative with physicians’ orders and interventions and better able to accept difficult prognoses and diagnoses. The educated, informed patient becomes a true partner in his or her care.

The critical question, of course, is whether or not these changes – patient and physician education, formalization of rules and laws related to end-of-life care and decision-making, and an end to or reduction in paternalistic treatment of lay people – can actually be implemented in Saudi Arabia. Researchers including Ten Have and Gordjin point out that there are many different perspectives on the globalization of ethics, with physicians holding widely differing views on what is and is not appropriate in terms of medical ethics. These researchers make the point that culture continues to exert enormous influence over medical ethics and that in highly conservative, traditional cultures that are likely to be both authoritarian and paternalistic, issues of patient rights and autonomy are given less attention that is typical in the West. This is an issue that will be addressed in greater depth in forthcoming chapters of this study.

Conclusions

ICUs represent a vital element in any healthcare delivery system in large measure because they are often the center of critical end of life decisionmaking. Such decisions are always emotionally charged and challenging for both caregivers and patients and their families. Nevertheless, in light of the principles of beneficence, physicians in almost all cultures perceive their role as involving efforts to make end stages of life as comfortable as possible for patients.
Some cultures such as that of Saudi Arabia address this issue by placing the burden of decisionmaking on physicians and failing to engage patients and their family members in the process. Other cultures such as that of the United States take a very different approach working to include patients and their families in end of life decisionmaking to the extent that is possible.

In this chapter, a brief comparison of the Saudi Arabian and United States’ approach to decisionmaking in the ICU has been presented. Other issues are also relevant such as the question of how each of these systems address palliative care for both adults and children. Palliative care practices provide an excellent point of comparison between two very different systems as does a discussion of withholding and withdrawing care.

The chapter concludes with the recommendation that the Saudi ICU approach could benefit from the inclusion of a number of the specific practices and philosophical perspectives that are common in the United States. Such a transition would be difficult but hardly impossible and in light of the fact that more and more Saudi physicians are receiving their training in the United States and throughout the West, such a change is likely to occur.
CHAPTER FIVE

COMPARISON BETWEEN PALLIATIVE CARE PRACTICES IN THE UNITED STATES AND SAUDI ARABIA

Introduction

Palliative care is universally acknowledged as a significant element of the end of life care pathway and as such occupies a central position in the health care systems of both the United States and Saudi Arabia. Research suggests that in many countries, physicians, nurses, and hospital or hospice administrators have joined together to develop effective, compassionate strategies and guidelines for delivering such care to the terminally ill and dying patient. The goal of palliative care is “to help people with serious illnesses feel better” while preventing or treating “symptoms and side effects of disease or treatment.”

Palliative care serves to treat the physical, emotional, social, practical, and spiritual problems that are associated with illness. It can be delivered in tandem with medical treatments designed to cure or treat a disease or other condition, given when the illness is diagnosed or throughout treatment, follow-up, or at the end of life. It is offered by medical and other professionals to individuals who can benefit from interventions designed to improve the quality of life for both the primary patient and his or her family members. Palliative care is generally an interdisciplinary team effort that can involve physicians, nurses, physio-therapists, occupational therapists, counselors/social workers/psychologists, and other health professionals who join with a primary care physician and/or hospital or hospice staff to offer an additional level of support during a time when most patients and their families experience some type of crisis.
The fundamental concept of palliative care speaks to the ethical orientation of virtually all medical systems regardless of culture or nationality. Researchers in both the United States and Saudi Arabia have acknowledged the importance of palliative care. No physician wants to see a patient suffer unnecessarily or for a long period of time. No physician would expect that a patient accept without some questions a lingering death. Because this is the case, it is particularly important for caregivers across the world to become comfortable with palliative care as a means of meeting the ethical obligations of the medical profession.

The World Health Organization (WHO) defined palliative care as having the following goals and objectives or elements:

- provides relief from pain and other distressing symptoms;
- affirms life and regards dying as a normal process;
- intends neither to hasten or postpone death;
- integrates the psychological and spiritual aspects of patient care;
- offers a support system to help patients live as actively as possible until death;
- offers a support system to help the family cope during the patient’s illness and in their own bereavement;
- uses a team approach to address the needs of patients and their families, including bereavement counselling, if indicated;
- will enhance quality of life, and may also positively influence the course of illness;
- is applicable early in the course of illness, in conjunction with other therapies that are intended to prolong life, such as chemotherapy or radiation therapy, and includes those investigations needed to better understand and manage distressing clinical complications.

These aspects of palliative care go well beyond questions of nationality or culture. They speak to the fundamental principles of medicine as articulated within all versions of the Hippocratic oath. They also appear on balance to acknowledge that there are some concerns relative to culture that may not necessarily be significant when it comes to providing care to the dying patient or assistance or support to his or her family members. Organizations such as the
World Health Organization, in assembling definitions and standards such as those presented above, necessarily take into consideration the ways in which different cultures may approach sensitive or potentially controversial subjects.

According to Delgado-Guay, Parsons, Palmer, and Bruera, interdisciplinary palliative care teams work with patients and their families with the intent of clarifying care goals, assisting in symptom management, and offering psychosocial and spiritual support. Treatments offered under the aegis of palliative care can include counseling, support groups, family meetings and conferences, and referrals to mental health professionals. They may also include medicine, nutritional guidance, physical and other therapies, and patient and family education. Meir emphasizes the fact that palliative care is focused on the alleviation of the suffering that patients and their families experience when death is near or inevitable; it is a care practice that may be delivered in hospice settings but it should not be confused with hospice itself.

As described by the National Palliative Care Research Center (NPCRC), palliative care is increasingly recognized as a health care specialty that is “both a philosophy of care and an organized, highly structured system for delivering care.” A growing body of research has demonstrated that palliative care can improve health care quality in three specific domains: relief of physical and emotional suffering; improvement and strengthening of patient-physician communication and decisionmaking; and “assurance of coordinated continuity of care across multiple healthcare settings – hospital, home, hospice, and long-term care.”

In many parts of the world, palliative care is conceptualized as a viable alternative to the intensive care system for end of life patients. Inevitably, however, palliative care practices tend to have developed more rapidly and extensively in countries such as the United States than in others including the Kingdom of Saudi Arabia. This chapter of the study serves to compare
palliative care practices of the two target countries, highlighting the potential benefits which
would accrue by incorporating elements of the American system into the Kingdom’s system.
Such a process would serve to support patient and family goals for the future, including hopes
for cure, life prolongation, comfort, and control.

When palliative care is addressed in the literature, one regularly finds that a discussion of
the ethical aspects of treatment with opioids is introduced. In many countries, including Saudi
Arabia, opioid prescriptions are sparingly provided even to alleviate the suffering of the dying
patient for whom no intervention will either reverse a condition or improve the quality of life or
prolong that life. Concerns regarding the addictive qualities of opioid prescriptions have, to some
extent, inhibited the ability of physicians in Saudi Arabia and other countries to take full
advantage of these pain relieving pharmaceuticals. Drug addiction and drug abuse are issues that
are treated differently in Saudi Arabia than they are in the United States. This must be taken into
account in any discussion in which comparisons of the United States and Saudi Arabia are
offered.

A. Palliative Care in the United States

i. Overview of Palliative Care: Extent of Programming

In the United States, a distinction is made between palliative care and hospice care. Hill
states that while both hospice services and palliative care programs are oriented toward provision
of symptom relief and pain management, hospice is a type of care that involves palliation
without curative intent. Patients in the United States who are most likely to be offered
palliative care services may present with such diseases or conditions as cancer, chronic or
progressive pulmonary disorders, renal disease, chronic heart failure, progressive neurological
conditions including stroke and its effects, or HIV/AIDS. In essence, palliative care unlike
hospice care acknowledges the possibility of symptom elimination, cure, and a return to health and well-being as distinct from an inevitable demise.\textsuperscript{370}

Additionally, the United States is home to an active movement focused on ensuring that patients with various conditions or needs have access to standardized, high quality palliative care in multiple settings including the home, the hospital, and the hospice. The Center to Advance Palliative Care (CAPC) has estimated that the number of palliative care teams in American hospitals alone increased from about 600 to 1,600 between 2000 and 2012.\textsuperscript{371}

It would be erroneous to suggest that the hospice movement in the United States has resulted in universal availability of hospice care. Acceptance of hospice services is fundamentally different from finding and deploying the resources needed to offer such services. This is particularly troubling in light of the fact that the massive baby boomer generation is rapidly aging and likely to need such care. In addition, it should be noted that palliative care is offered frequently in American ICUs and other hospital units. This leads to the conclusion that palliative care does not require a hospice setting. It can and should be integrated into the full range of inpatient services that are offered by a medical institution.

One of the reasons why palliative care in the United States has become such a critical focus of service expansion in the medical field relates to the fact that by 2030, fully 20 percent of the total U.S. population will be over the age of 65. The NPCRC stated that while for most, the years after age 65 are a time of good health, independence, and integration of a life’s work and experience, “eventually most adults will develop one or more chronic illnesses with which they will live for years before death.”\textsuperscript{372} These years can be characterized by a combination of physical and psychological symptom distress, high family or social support needs, and progressive functional dependence and frailty. Consequently, in light of this and the fact that
medical care for patients with advanced illness is not without significant flaws, palliative care programs and protocols have become increasingly significant in the United States and every U.S. medical school is now required to provide training in palliative medicine.¹³³

Data provided by the CAPC helps to illustrate the growth and expansion of palliative care programs in American hospitals. The 2015 Report Card from the CAPC shows a continued increase in the number of hospital palliative care teams in the United States:

- 67 percent of U.S. hospitals with fifty or more beds report palliative care teams, up from 63 percent in 2011 and 53 percent in 2008.
- The number of states with A grades (defined as more than 80 percent of the state’s hospitals reporting a palliative care team) also increased, from 3 percent in 2008 to 17 percent in 2015
- For the first time no state has a grade of F (defined as less than 20 percent of a state’s hospitals reporting a palliative care program). Important gaps still remain.

One-third of U.S. hospitals with fifty or more beds report no palliative care services, and one-third of the states received a grade of C or D.¹³⁴

These data do support the assertion that despite universal approval of palliative care in the United States and equally universal belief in its efficacy as part of end of life care, not every hospital currently offers such care. The data also demonstrate that there are substantial variations to be observed when palliative care services in one institution are compared to such services in another. Nevertheless, one can conclude that palliative care is taking root within the American healthcare system and that this particular trend is likely to continue.

CAPC indicated that nonprofit hospitals in the United States when compared to both public and for-profit hospitals are more likely to have palliative care beds available to their patients. This holds true regardless of the actual size of the hospital. For profit hospitals are less likely to offer palliative care beds than either public or nonprofit hospitals. As public hospitals
increase in size relative to the total number of beds available, they also increase the number of palliative care beds available.\textsuperscript{375}

Additionally, CAPC identified the percent of institutions with palliative care by region and by type. The organization pointed out that palliative care services are more readily available in urban areas than in rural areas and similarly more available in suburban communities that in rural communities. Teaching hospitals are also more likely to offer palliative care services in the United States.\textsuperscript{376}

Overall, however, CAPC asserts that based on its national survey suggests that the entire U.S. hospital system – including public, non-profit and for-profit institutions – deserves a grade of no more than “B” despite overall growth in provision of such services.\textsuperscript{377} A call to action on this issue was initiated under the aegis of the National Consensus Project for Quality Palliative Care of the National Quality Program. This organization has worked over the past several years to create a set of Clinical Guidelines embodying 38 preferred practices for palliative care as well as hospice care. The National Consensus Project released a second edition of its recommendations in 2009, calling for further standardization of care practices to mesh with research.\textsuperscript{378}

Joining with The Joint Commission (TJC), formerly known as the Joint Commission on Accreditation of Healthcare Organizations, these guidelines and elements of performance emphasize the continuum of care involving pain and symptom control, psychosocial distress, spiritual issues, and practical needs in a culturally sensitive, appropriate and understandable manner.\textsuperscript{379} Palliative care guidelines include recommendations for various patient populations including children and adults, individuals with congenital injuries or conditions leading to dependence on life sustaining treatments and/or long-term supported care, and individuals with
progressive chronic conditions or people living with life limiting injuries from accidents and other forms of trauma. The National Consensus Project affirms that “palliative care is both a general approach to patient care that ideally should be routinely integrated with disease modifying therapies and a growing practice specialty for appropriately trained health care professionals.”

Here, once again, it is worth pointing out that the United States is a culturally diverse and heterogeneous society. While one might identify some fairly broad characteristics that help to define or at least identify the nature of culture in the United States, there are many different racial, ethnic, national, and linguistic groups in American society. These groups present often radically different beliefs about health and wellness. They may well disagree as to the proper role of medical care and hold radically different views on how the end of life should be approached and dealt with.

Other research also addressed the growth of palliative care in the United States. For example, Hughes and Smith pointed out that palliative care is one of the most rapidly growing fields of health care in the United States in the past decade. This is due according to these researchers to increased sensitivity among medical caregivers to the needs of patients and their families during periods in which health crises occur. Hughes and Smith further noted that while early palliative care programs and models tended to be linked to hospice care, this has gradually changed in that caregivers are increasingly cognizant of how palliative care increases patient and provider satisfaction, fosters better symptom control, and more discernment and honoring of choices regarding both treatment and end of life decisions.

A study by Dumanovsky, Augustin, Rogers, Lettang, Meier, and Morrison examined variation in access to hospital based palliative care, employing data from the American Hospital
Association Annual Surveys for 2012 and 2013, the National Palliative Care Registry, the Dartmouth Health Care Database and Atlas, and the U.S. Census Bureau. Additionally, the researchers employed Web searches and telephone interviews of hospital administrators and program directors to gather their data. The data included multiple elements related to program services, revenues and expenses, beds and utilization, types of services provided, and overall hospital operation concerns.

According to Dumanovsky, et al, hospitals of at least 50 beds were included in the study although all rehab hospitals, psychiatric hospitals, sub-acute and chronic care facilities, and hospitals falling under federal control were not included. Overall, results indicated that some 67 percent of U.S. hospitals located in the 50 states and the District of Columbia that had more than 50 facility beds also maintained a palliative care program. As hospital size increased the study revealed that 90 percent of hospitals with 300+ beds were found to have palliative care programs as compared to 56 percent of hospitals with fewer than 300 beds.

The research revealed that tax status was a significant predictor of whether or not an institution would have a palliative care program. Not for profit hospitals and public hospitals were respectively 4.8 times and 7.1 times more likely to maintain such a program than for profit hospitals. When considering region, Dumanovsky, et al found that palliative care penetration was highest in New England where it was found in 88 percent of hospitals, the Pacific states (77 percent of hospitals), and the Mid-Atlantic (also 77 percent of hospitals). Palliative care program penetration was lowest in the West South-Central Region at 43 percent and East South Central at 42 percent of hospitals.

The results reported by Dumanovsky, et al also generated grades for each of the 50 states and the District of Columbia. Ranging from A for states in which over 80 percent of hospitals
had palliative care programs to Fs given to states with 20 percent or fewer hospitals having such programs, these grades confirm the data presented above in this chapter. Not surprisingly, the larger the institution and the more densely populated its service area, the more likely it was to receive a letter grade of B or A.386

Thus, while much of the literature suggests that the United States has in fact taken a lead role in advancing palliative care programming, it should be clear that the progress made thus far does not represent a universal approach to offering such care in all possible settings. The Hospice and Palliative Care Association of New York, for example, states that caregivers in multiple medical fields are concerned that there is limited access to palliative care services in a number of local settings, including communities with smaller hospitals, rural communities, or communities that are primarily served by for profit hospitals and/or hospitals falling under federal administrative umbrellas.387 It is therefore clear that despite its prominence as a locus for the delivery of palliative care, the United States health care system does need to expand its engagement with this vital service.

**ii. Models of Palliative Care**

Within the general context of the clinical practice guidelines promulgated by the National Consensus Project, there are many number of models of palliative care programs that are being employed in different settings. Fundamental to each of these models are eight particular domains:

- Structure and processes of care.
- Physical aspects of care.
- Psychosocial and psychiatric aspects of care.
- Social aspects of care.
- Spiritual, religious, existential aspects of care.
- Cultural aspects of care.
- Care of the terminally ill or imminently dying patient.
- Ethical and legal aspects of care.

Palliative sedation is a technique for providing a sedative for end of life care to patients experiencing intractable pain. It is a care element that comes into use when an individual, confronting an inevitable and impending demise, seeks to reduce the pain he or she is feeling and may in fact be willing to seek a level of sedation that will effectively result in a coma-like or profound sleep state until physical death actually occurs.

Palliative sedation in nursing anesthesia and its ethical connotations and implications, palliative sedation is in some cases seen as controversial because it may remove the patient’s ability to exercise the autonomy to change a decision once treatment begins. Additionally, palliative sedation often stirs emotion and generates moral and ethical debate in which it is suggested that palliative sedation can be administered for assisted suicide or euthanasia.

Tadeusz Pacholczyk, the Director of Education at the National Catholic Bioethics Center, examined the question of palliative sedation through a qualitative research effort that drew not only upon scholarly work in the field of medicine and nursing, but also on a variety of ethical constructs and relevant Christian theology. It is the contention of Pacholczyk that the ethical dilemma inherent in palliative sedation centers on the conflict between the legitimate need to remediate pain and suffering while also ensuring that the dying process appropriately incorporates and takes cognizance of that suffering as an inevitable aspect of life. This analyst, who is a Catholic priest, acknowledges that the Catholic Church has never proposed that an
individual has a moral obligation to refuse pain medication as a means of purification and mortification. Appropriate pain management, including palliative sedation is not in his view antithetical to the Christian world view of suffering as redemptive.390

Pacholczyk also asserts that permanent total sedation is a new and artificial form of living death that is distinct from traditional high dose opioid therapy. It does prohibit the dying individual from participating in the events of his or her own death and therefore reduces individual autonomy. Unfortunately, Pacholczyk does not provide a definitive ethical assessment of this treatment.391

Another qualitative study, by Jansen, explored ethically contentious palliative sedation and differentiates between it and slow euthanasia. This analyst (whose work is included to illustrate how healthcare practitioners often approach the issue) argues that clinical intentions in end of life contexts must be clearly understood. Noting that the circumstances under which a physician agrees to administer doses of medication that will potentially hasten the death of a patient are rare, Jansen claims that extraordinary clinical interventions must always be carefully considered before they are recommended to a patient.392

This study, like that of Pacholczyk, represents a very small sample of the literally hundreds of articles examined with respect to the fundamental ethical meaning or significance of palliative sedation. Like the work by Wolf, the work by Jansen approaches the topic from the perspective healthcare professionals whereas Pacholczyk focuses less on professional responses than on the overarching ethical implications of masking the redemptive suffering potentials that are associated with death and dying.

These three articles, selected as noted above from a number of similar studies, do not describe any specific inclusion methodology but are presented as the scholarly work of individuals who
appear to have read broadly and deeply on the subject of palliative sedation. Each article advances an argument. Wolf alone of the three writers provides a case report of providing palliative sedation to a terminally ill patient. This case study tends to affirm the importance of ensuring that patients are fully cognizant that once initiated, palliative sedation is unlikely to be reversed.\(^{393}\)

Multiple quantitative studies and/or qualitative studies that generated new data were identified in the literature. A sample of such studies was selected for discussion herein to illustrate the issues that are considered significant by caregivers and ethicists alike.

Patel, Gorawara-Bhat, Levine, and Shega conducted four focus groups with nurses likely to have had exposure to palliative sedation. Of the sample of 31 nurses, 87 percent were female, 58 percent were between the ages of 36 and 55, and more than 54 percent reported 10 or more years of providing patient care. They identified knowledge, skills, and guidelines as key considerations for implementing palliative sedation and called for a combination of comprehensive institutional policies and adequate training.\(^{394}\)

Patel, et al stated that nurses in such fields as oncology, intensive care, and hospice were generally supportive of palliative care for the suffering terminally ill patient. These professionals expressed relatively minimal concerns regarding palliative care as a slippery slope facilitating euthanasia and did acknowledge that it was incumbent upon institutions to provide staff members with enhanced understanding of where, when, and how palliative care is appropriate.\(^{395}\)

Leboul, Aubry, Peter, Royer, Richard, and Guirimand collected data via a qualitative study in which multi-professional focus groups consisting of 35 medical and paramedical providers were featured. Centered in two French hospitals, the study sought to gain a better understanding of how healthcare givers view sedation practices in French palliative care units.
The study revealed that many caregivers have a high level of uncertainty with regard to the medical, psychosocial, and ethical justification for such sedation. Interestingly, Leboul, et al concluded that this uncertainty generates both moral distress and a psychological burden for caregivers which creates suffering in the workplace that can only be ameliorated through more comprehensive institutional policies.\textsuperscript{396}

Bruinsma, Van der Heide, Van der Lee, Vergouwe, and Rietjens performed an observational questionnaire study among relatives of a consecutive sample of patients who died a non-sudden death in either a cancer institute or a hospice in Rotterdam. Relatives of 151 patients who had received palliative sedation and relatives of 90 patients who had not been sedated at the end of life participated. The goal of this study was to examine how patients’ families evaluated the patient’s dying experience and their own well-being after the patient’s death. Results indicated that no negative effects linked to the use of palliative sedation were reported.\textsuperscript{397}

This work by Bruinsma, et al approaches palliative sedation from the perspective of family members and not the dying patient or caregivers. It was concluded herein because it offers a unique perspective on a complex subject. The research revealed that this randomized sample of subjects drawn from a pool of 564 possible families viewed palliative sedation as a blessing for those patients whose pain was substantial and who therefore sought relief.\textsuperscript{398}

Swart, Van der Heide, Van Zuylen, Perez, Zuumond, and Van der Moss, et al investigated considerations concerning indications for palliative sedation and the issues influencing these considerations. A sample consisting of 54 physicians and 36 nurses working in general practice, nursing homes, and hospitals participated in semi-structured interviews. Results indicated that caregivers approach consideration of continuous palliative sedation after assessing physical symptoms and non-physical problems; caregivers consult with patients and family
members. The study is useful in identifying the fact that many caregivers see palliative sedation as useful not only for relieving severe physical symptoms but also for reducing psychological and existential distress.399

This relatively small sample of the many studies available on palliative sedation serves to position the discussion of this practice within the context of personal and professional ethics and concerns for reducing the physical suffering experienced by many dying patients. The studies as a whole affirm the fact that even professional caregivers experience ethical qualms about palliative sedation and its impact on all stakeholders including caregivers. The issue is challenging not the least because there are no hard and fast guidelines as to when, where, and how palliative sedation is likely to be universally appropriate. Absent from the studies discussed herein and impossible to acquire are the views of those individuals who have experienced palliative sedation.

Just as is the case with hospice care, model palliative care programs focus on close coordination and partnerships among members of multidisciplinary teams. Together, hospice and palliative care share systematic treatment of pain and symptom control, psychosocial distress, spiritual issues, and practical needs. Such programs each include not only the patient, but also the significant others or family members whose engagement with the patient is vital during treatment or during end of life issues.400

Palliative care has a specific place or position in the course of illness. It intersects with both life prolonging therapies and with hospice services. Palliative care follows a diagnosis of serious illness whether or not the illness is expected to be terminal in the foreseeable future. Certainly, hospices that exist almost exclusively to provide end of life care in the United States offer palliative care along with other services. Institutions that offer life prolonging therapy on
an inpatient or outpatient basis also provide palliative care. In essence, palliative care spans multiple service sectors in the practice of medicine.\textsuperscript{401}

As described by Rome, Luminais, Bourgeois, and Blais, the traditional medical treatment model is now dichotomous with physicians offering curative or aggressive treatment initially and initiating comfort care only when other measures have failed. Palliative medicine, however, establishes goals designed to relieve pain and suffering in all stages of disease or subsequent to an injury and is not limited as is hospice to end of life care.\textsuperscript{402}

Hospice care is a specific service delivery system and model providing palliative care when life expectancy is six months or less and when curative or life prolonging therapy is no longer indicated. Consequently, “not all available therapeutic palliative care modalities are provided within the hospice service delivery system.”\textsuperscript{403} Regardless, however, of the setting in which it is offered, palliative care is operationalized via the effective management of pain and other distressing symptoms while simultaneously incorporating psychosocial and spiritual care with consideration of patient and family needs, preferences, values, beliefs, and culture.\textsuperscript{404}

Palliative care models facilitate interactions between physicians and patients to a much greater extent than is found in the typical ICU.\textsuperscript{405} By including social workers, psychiatrists and psychologists, priests and ministers or rabbis and other spiritual caregivers, palliative care seeks to focus on spiritual as well as physical needs of patients.\textsuperscript{406} In the United States, spirituality may or may not be practiced within the framework of traditional or formal religious belief systems. Palliative care models therefore tend to incorporate non-medical caregivers.\textsuperscript{407} Many hospitals and hospices offer on-site spiritual counseling to patients and their families or significant others, and these counselors are often integrated into palliative care models.
Morrison described hospital centered palliative care programs in the United States as follows: “The two primary models of palliative care that exist within hospitals are interdisciplinary consultation teams and inpatient units. The number of hospital palliative care teams has grown rapidly and as of 2011, 63% of all US hospitals reported a palliative care team and over 85% of hospitals with over 300 beds.”

Morrison also stated that there is enormous variability in terms of the number of palliative care beds available not only across institutional types but within institutional types. As noted above, hospitals that provide for interdisciplinary teams tend to be better able to provide effective palliative care than those that do not. Other variables including geography, hospital size, hospital type, and tax status impact on the provision of palliative care services. The interdisciplinary team is a critical element of palliative care programming regardless of the setting in which it is provided; hospitals and hospices, as well as home-based programs, all share this characteristic.

Developments in the delivery of palliative care have been forthcoming. According to Morrison, “Newer models of palliative care focus on delivering services to patients living in the community with serious illness who are not eligible for hospice. New payment models under the PPACA that penalize hospitals for unwanted and unnecessary readmissions, bundled payment plans that capitate both inpatient and outpatient costs, and efforts to reduce hospital mortality have led to the development of new models of care.” These newer models include:

- ambulatory consultation clinics in which interdisciplinary teams provide palliative care consultation to treating physicians;
- interdisciplinary home care provided through certified home health agencies or hospices outside of the Medicare Hospice Benefit;
- palliative care teams supported by capitated managed care plans, and
- hospital-based teams that provide physician home visits.\textsuperscript{411}

One must look to the Patient Protection and Affordable Care Act of 2010 for an understanding of the growth in models of palliative care. This legislation has forever changed the ways in which medical care is being delivered in the United States and as significantly has affected how such care is financed. The Affordable Care Act ushered in an era of health care reform that was designed not only to reduce the cost of health care, but also to improve access to such care and to establish improved care delivery systems.\textsuperscript{412}

Palliative care programming did in fact derive from hospice care in the United States. The first formal American hospital based palliative care consultation service was established at the Wayne State University School of Medicine’s program at Detroit Receiving Hospital and was followed shortly by a program that was established by Dr. Declan Walsh at the Cleveland Clinic in Cleveland, Ohio.\textsuperscript{413}

The program established by Dr. Walsh generated a number of innovations including the establishment of the first clinical and research fellowship in palliative medicine, the development of an acute care palliative medicine inpatient unit, and the maintenance of an Integrated Center of Oncology and Palliative Care. Over the next several years, other university medical centers and well known hospitals also created and implemented their own palliative care programming. Institutions such as the Medical College of Wisconsin, the Memorial Sloan-Kettering Cancer Center, Mount Sinai School of Medicine, and the Lillian and Benjamin Hertzberg Palliative Care Institute are a few of the examples of such programs. \textsuperscript{414}
The Joint Commission has subsequently established an advanced certification program for palliative care that is responsible for recognizing and certifying hospital inpatient programs. Working together with the National Consensus Project, the Joint Commission also seeks to establish what will ideally become universal, verifiable guidelines for the delivery of multidisciplinary palliative care services in hospitals and other settings.415

Board certification for physicians in the United States with respect to the palliative care specialty was originally obtained through the American Board of Hospice and Palliative Medicine. As more has been learned about palliative care and the roles to be played by physicians from multiple specialties and subspecialties, there are now 11 different specialty boards that certify physicians for palliative care specialization. There are also more than 50 fellowship programs available for individuals who have successfully completed a primary residency. Nurses in the United States are offered continuing education credits through specific training programs such as those offered by the End of Life Nursing Education Consortium.416

It should be noted that in the United States, palliative care services are offered to patients without any restriction with respect to disease or prognosis. As various researchers including Delgado-Guay, et al have pointed out, this is yet another way in which palliative care in the United States differs from hospice care which requires that two physicians certify that a patient has less than six months to live if Medicare reimbursement is to be obtained.417

Regardless of where palliative care is offered – in hospital inpatient or outpatient settings, hospice, or at home – palliative care services focus on alleviating suffering. This means that one must address psychological distress and lack of social support as well as physical pain because optimal pain relief is not possible unless or until all elements of total pain are addressed.418 Integral as well are psychosocial, bereavement, and spiritual support. It is believed that
physicians, psychologists, nurses, social workers, and ministers each play critical roles in addressing these issues; the original focus is on the patient but palliative care takes into account the needs of family members and significant others both during the care delivery process and, in the event of death, the bereavement process.

Models of hospital based palliative care services include but are not limited to consultation services, inpatient palliative care units, and co-management models. Meier and McCormick defined these specific hospital based models. Consultation services are the most common in palliative care and consist of physicians, nurse practitioners, social workers, psychologists, chaplains, pharmacists, and volunteers. Inpatient palliative care units may assume either primary responsibility for patients or continue in a consulting mode; this approach is most appropriate for patients with difficult to control symptoms, medical needs that cannot be optimally managed in other settings, families needing a high level of support, and patients who are imminently dying. Co-management models are integrated programs that are often positioned in intensive care units. These models tend to be led by surgical and trauma intensive care professionals. All three of the models do at times include the services of multiple specialists.419

Of course, as Meier and McCormick also note, there are substantial detailed variations in program models when individual efforts are examined – something beyond the scope of this study. 420

Thus, whether offered in hospital, hospice, ambulatory or home settings, palliative care programs in the U.S. address specific goals and objectives, to wit:

● Adequate control of pain and other symptoms

● Achieve a sense of control

● Relieve burden on family members and strengthen relationships
● Gain a realistic understanding of the nature of the illness

● Understand the pros and cons of available treatment alternatives weighed in context of the patient’s goals and values

● Name decision makers in case of loss of decisional capacity

● Have financial affairs in order

In the United States, the palliative care system recognizes that spiritual needs are as significant as other needs during the crises that center on illness or trauma as well as end of life processes. Spiritual needs consist of the needs for self-integrity, repentance and forgiveness, the need to be valued, and the need to accept death. Spirituality focuses on dealing with attitudes, hope, faith, and belief, and the purpose and meaning of life. Patients are encouraged to employ their belief systems and any religious counselors in learning to cope with their situation. One of the key characteristics of the American system is respect for diversity of spiritual beliefs and respect for individual autonomy with respect to choosing a religious path. Palliative care professionals are responsible for exhibiting sensitivity to the cultural and spiritual desires of patients and refraining from imposing their own views on them.

There is no doubt in the view of most researchers including Morrison that the benefits of palliative care are quite extensive; not only do patients and their significant others experience positive outcomes from the delivery of palliative care services, research also supports the efficacy of such services in facilitating multidisciplinary cooperation and communication among caregivers.

A study by McAteer and Wellbery examined the benefits, best practices, and barriers impacting upon the delivery and use of palliative care services in the United States. According to these analysts, despite documented benefits, palliative care is underutilized in the management of advanced or terminal illnesses in the United States. These researchers estimated that more than
one million deaths accounting for 45 percent of all deaths in the United States in 2011 occurred in hospices. While this represents a gradual upward trend, fully 36 percent of those patients either died or were discharged within seven days of admission and nearly two-thirds or 63 percent received hospice care for less than one month.

There are several factors that may account for underutilization of hospice care and palliative care in other settings. This includes confusion about terminology, limited understanding of its intent and scope, questions regarding costs and insurance coverage, and potential mistrust due to perceived economic motives. Some physicians are also uncomfortable with end of life conversations because of fear that this may deprive patients of hope.

The potential barriers and solutions to physician referrals to palliative care have been identified in the literature. Critical barriers include confusion about terminology, general misperceptions about intent and the scope of hospice care, belief that palliative care is only available in inpatient hospice centers and not in homes or skilled nursing facilities, and fears that palliative care may deny patients life prolonging therapies or compromise access to costly life prolonging treatments. The solution to this set of concerns is to clarify to patients and their significant others the fact that palliative care is not necessarily a permanent therapeutic approach and all decisions about such care can be modified as needed. Other barriers include mistrust of healthcare professionals and the belief that hospice care is economically motivated, prognostic uncertainty regarding disease trajectories, and a tendency on the part of both physicians and patients to be overly optimistic about a prognosis. In each of these instance, physicians should educate patients and their significant others about palliative care, illness trajectories, hospice options, and goals of care.
The development of palliative care services has been largely influenced by the U.S, fee-for-service system. Because current reimbursement mechanisms fail to provide support for the interdisciplinary team beyond physician reimbursement, to date, palliative care teams have largely developed within hospitals where the demonstration of the enhanced quality provided by palliative care teams in combination with significant cost savings to hospitals has provided a strong business case to support their development. Unlike the ambulatory care settings, hospitals receive a lump sum Diagnosis Related Group payment for an episode of patient care. Thus, interventions like palliative care that reduce overall patient care costs for hospitals improve profit margins. Indeed, an average-size US hospital can save over US$3 million per year by having a palliative care team.425

Economic benefits, therefore, are significant. That being the case, it is also true that palliative care provides symptom management and quality of life improvements that can prolong life and generally lead to an increase in physical, spiritual, and psychological well-being. McAteer and Wellbery state that these benefits include reducing depression and symptom burden, assisting patients in feeling that they have a higher level of control over their lives, and improved utilization of health care resources.426

These benefits also extend to caregivers, family, and friends. These key actors also perceive themselves as more satisfied with the quality of care made available through palliative services. Family members and friends of patients receiving palliative care also express a sense that their own needs have been given greater consideration than would have otherwise been the case.

Finally, in addition to the reduction in costs for care that are associated with palliative care services in all settings, such services have been instrumental in generating a variety of new
assessment tools and therapeutic techniques that are in and of themselves beneficial to members of the medical profession. The Palliative Prognostic Score and the Flacker Mortality Score as well as the Patient-Reported Outcome Mortality Prediction Tool are increasingly used by clinicians in determining care plans and in conducting research to assess care outcomes.427

B. Palliative Care in Saudi Arabia

i. Overview of the Section

Palliative care is still a relatively new concept in the Middle East. It was first introduced in Saudi Arabia in 1992 and only recently in countries such as Qatar, Bahrain, and the UAE. Although the majority of Middle-Eastern countries, including Palestine, Iraq, Oman and Lebanon are in the capacity building phase, others such as Saudi and Jordan already have localized provision. In the absence of any of the countries of the region approaching integration with the mainstream service providers, Saudi Arabia and Jordan are currently setting examples of achievement in the field. There are still countries with little or no known Palliative Care activity (Yemen and Syria). Political issues, scarcity of resources, and lack of education and awareness seem to be the common factors restricting the progress of this field in most countries. In order to improve the suboptimal PC services in the ME, emphasis should be directed toward providing formal education to professionals and raising awareness of the public. It is also necessary to put all differences aside and develop cross-border collaborations, whether through third party organizations such as the Middle East Cancer Consortium (MECC) or otherwise. These issues are discussed below.

ii. The Case of Saudi Arabia and Palliative Care

It is widely recognized that the need for palliative care around the world is immense and, simultaneously, that palliative care is in many locales a misunderstood concept among health
practitioners. Speaking to this issue, Aljawi and Harford make note of the fact that approximately 60 million deaths from all causes occur annually in the global community with about 80 percent of these deaths occurring in low income and middle income countries where palliative care services tend to be lacking. The problem in the view of Aljawi and Harford is that in many countries there are barriers to the rational use of opioid analgesics as well as barriers to treatment derived from religion and culture. Further, Aljawi and Harford make note of the fact that palliative care in Muslim countries is invariably approached from the perspective of both religion and culture and, more often than not, is relatively unavailable.

In fact, research suggests that at the heart of resistance to palliative care services in many largely Muslim countries is based upon religious beliefs which emphasize the sanctity of life and reject activities that are perceived as failing to prolong life. One of the cultural barriers known to hinder the development of palliative care in Muslim majority countries in general and in Saudi Arabia in particular is the misperception that palliative care reflects a determination that it is time to literally give up on life and to accept the inevitability and immediacy of death. Silberman, et al note that in Western societies, “death has become medicalized and curative procedures are often prioritized ahead of palliative care…. In Western culture there is a recognizable lack of acceptance of death, leading to reluctance in seeking end of life care.”

While Islamic societies may be more accepting of death as inevitable, this does not necessarily mean that such countries have embraced palliative care. Silberman, et al identify the primary barriers to the use of palliative care in Muslim countries as consisting of three areas:

- Lack of health policies in support of palliative care development.
- Lack of relevant training of healthcare workers.
- Poor accessibility of palliative care drugs.
Silberman, et al emphasized that “it is a time of an increasing interest in palliative care worldwide and in the Middle East.” Further, this analyst takes the position that there are many substantial barriers in this region of the world to palliative care services that derive from variations in religion, education, and traditions. Often, as has been noted elsewhere herein, people in this region try to avoid telling patients that they are dying. This appears to be especially true in Muslim communities wherein both physicians and healthcare consumers and their families are uncomfortable with end-of-life conversations and decision-making.

One analyst put it this way: “Still there is an impression that palliative care of a terminally ill is like euthanasia. However, the palliative care may be the moral and ethical alternative of euthanasia for some.” Further, many Muslims are concerned about the use of morphine in palliative care when morphine is not itself an accepted treatment option for the patient’s underlying condition. In some Saudi hospitals such as King Faisal Hospital, the hospital has a protocol of “No Code” that is very like the Western DNR order; when patients with this mark on their chart approach death, it is allowed to proceed with dignity and without intervention.

One objection to palliative care often raised in the Muslim world is the fear that the purpose of such care is to overtly obtain organs for transplantation. In the Qur’an, there is a verse which supports organ transplantation: “Whosever gives life to a soul shall be as though He has given life to mankind.” Many Muslim scholars believe that this is an acceptable based on the principle that the needs of the living override those of the dying or already dead. That said, palliative care is linked in the view of some less educated Muslims to the notion that organ harvesting is its focus – and this can be influential in preventing patients and their families from accessing such care.
Other barriers to palliative care service delivery in the Middle East and Saudi Arabia have also been identified. A lack of supported policies promulgated by the Saudi government is one of those barriers that Al-Shahri and Al-Khenaizan identified, pointing out that Saudi Arabia has localized provision of palliative care in a small sample of government operated medical centers and hospitals but failed to promote countrywide policies on this important issue.\textsuperscript{436} However, assessing the state of palliative care in a given location is complicated at best and comparing one location to another is even more difficult because comparable data may not be easily accessible.

A study by the International Observatory on End of Life Care (IOELC) focused on the Middle East. Reported by Bingley and Clark, this study revealed that countries of the Middle East and other Muslim majority countries could be characterized with respect to palliative care as having no known activity, engaged in capacity building, focused on localized provision, or approaching integration.\textsuperscript{437} In the case of Saudi Arabia, this research indicates that localized provision alone has become common with respect to the availability of palliative care services. The problem is that while acknowledgement of the viability and importance of palliative care appears to be relatively widespread in Saudi Arabia, there is still reluctance among physicians to make recommendations regarding such care and the use of opioid analgesics which are interpreted by many as an indication of the futility of further service or treatment.\textsuperscript{438}

Al-Alaiyan and Al-Hazzini have pointed out that many Saudis are reluctant to use palliative services because they are concerned that accessing these services will position them as cruel, heartless, and somehow anxious to hasten the end of life for a family member; these researchers note that this is particularly the case when palliative care services are being requested for children in neonatal and other pediatric intensive care units.\textsuperscript{439} There is a cultural bias against
palliative care services in the Kingdom of Saudi Arabia for this reason and because of the
aforementioned perception on the part of some Saudi that palliative care is a de facto admission
that one has given up on the possibility of life.

One must acknowledge as does Abduari that palliative care is an isolated service within
the Saudi healthcare system.440 This particular analyst also identified specific issues and
challenges that complicate the delivery of palliative care in the Kingdom, dividing these
challenges and issues into four categories: policies and regulations, medication availability,
culture and public awareness, and education of physicians and nurses. Specifically, with respect
to policies and regulations, Abduari described the following concerns:

- A lack of laws defining palliative care as part of the healthcare system.
- Insufficient national standards of care including palliative care.
- Limited clinical guidelines and protocols on palliative care.
- No national strategy on palliative care implementation across the healthcare system
  infrastructure.441

In terms of medication availability, Abudari pointed out that there is limited availability
of opioids and other palliative care medications in the primary healthcare sector, an issue made
more challenging by policy restrictions on prescribing and dispensing such medications as well
as a lack of training of nonspecialized palliative care professionals regarding the safe use of such
pharmaceuticals.442 Further, there are cultural misconceptions regarding the use of opioids for
pain relief and no effort is being made at the present time to enhance public awareness of the
usefulness of such pharmaceuticals.

Inadequate education emerges in the view of Abudari as one of the most significant
barriers to the delivery of quality palliative care. Neither nurses nor physicians in the Kingdom
appear to have taken required courses on palliative care practices. There are also inadequate programs for continuing education of both physicians and nurses with respect to palliative care in domestic medical and nursing education institutions.443

Part of the problem was identified by Al-Shahri, who suggested that culture matters enormously when one is discussing palliative care. This analyst says that while there are a growing number of tertiary hospitals in the Arab world, nursing homes, hospices, and daycare centers tend to be relatively rare in such countries. This is due to several factors. In Saudi Arabia, the small number of geriatric care facilities that are available are largely viewed as homes for abandoned elderly. Families with a negative view of these institutions tend to admit elderly relatives to a tertiary hospital where sophisticated technologies and therapies that are capable of prolonging life are available. In essence, “hospitals are probably viewed positively because of the hoped for outcome expected from them… while geriatric or palliative care facilities are viewed negatively because of the feared outcomes associated with them (namely, death).”444

Al-Shahri pointed out further that “it should not be a surprise if a community in an Arab country labels a standalone palliative care center soon after its inauguration as a ‘death center.’”445 There is a more generally favorable response to palliative care services in the Kingdom when these services are delivered in hospital settings as opposed to standalone centers. While this situation may be changing, the fact is that relatively few Saudi hospitals offer palliative care services.

The first palliative care service in Saudi Arabia was begun at King Faisal Hospital in 1992. The King Faisal Specialist Hospital and Research Center in Riyadh was the first hospital in the Kingdom to offer palliative care for both adults and pediatric patients. Additionally, this particular hospital provides a variety of state of the art diagnostic and treatment services as well
as supportive services for patients and their families. Nevertheless, Nixon notes that much of the staff at this flagship Saudi medical center consists mostly of Western doctors and nurses which functions as a barrier to the acceptance of end of life announcements on the part of family members of Saudi patients.\textsuperscript{446} Job openings for palliative care practitioners abound in the Kingdom, where few Saudi physicians or nurses appear to be focused on this specialization. This may, to some extent, help to explain resistance among Saudi healthcare consumers to palliative care in general and stand-alone care centers in particular.

There are also concerns expressed by Nixon with respect to the limited availability of opioids, essential drugs used in treating pain that is often found among patients with terminal illnesses such as cancer and which form a fundamental element within the delivery of palliative care. Nixon notes that these essential drugs are not widely available to patients at the national level even though they are available within King Faisal Specialist Hospital and a small handful of other Saudi medical centers.\textsuperscript{447} Association of opioid use with illicit drug use – which is strictly forbidden in Islamic communities – may account for this barrier to palliative care. Opioid use is becoming more common in the Kingdom in the context of cancer treatments, and this is promising.

At the Princess Norah Oncology Center, palliative care service was formally initiated in 2001 with both adult and pediatric patients designated as targets of the program. At this institution, a Palliative Care Section was established. It includes the creation of interdisciplinary teams consisting of one or more doctors, nurses, social workers/psychiatrists, spiritual advisers, pharmacists, and personal support workers. Positioned as an autonomous unit within the hospital, the Palliative Care Section is nevertheless regarded as a supportive and functions under the guidance of primary care physicians.\textsuperscript{448} This example serves to illustrate the fact that palliative care...
care in the Kingdom remains subordinate to other healthcare specialties. This is not the case elsewhere in the world, where palliative care is a unique specialization for both physicians and nurses.

Of course, one cannot overemphasize the fact that Islamic principles and Islamic bioethics inform most medical decisions in Saudi Arabia. As has been emphasized throughout this study, Muslims believe that everything that occurs in one’s life takes place according to the will of Allah. Many but not all Muslim patients do not accept scientific explanations concerning the probability that they or a loved one will either recover from a serious illness or trauma or is likely to die as a consequence of such events. Muslim patients are convinced that while physicians are geared toward assisting them in achieving health and maintaining well-being they tend to be equally convinced that the ultimate fate of the individual is determined not by human interventions or actions but by Allah.449

Sanctity of life is the foundation of the principles that Muslims (both healthcare professionals and their patients) employ as they develop end of life decisions.450 This principle postulates that each and every day that an individual lives is a gift of great value from Allah and as such must be respected. This leads a number of health care consumers who are devout Muslims to request treatments that are ultimately futile and which may in fact have the effect of actually hindering efforts by physicians to prevent the prolongation of the dying process or to alleviate often quite significant suffering on the part of patients.451

Even when they are informed that a requested treatment will only prolong life temporarily while potentially inducing substantial pain and unnecessary suffering, many Saudis continue to ask physicians to provide them with such care. This is a concern that Gatrad and Sheikh identified as critical in establishing the philosophical environment in which Saudi
hospitals have begun the process of implementing palliative care programming and recommending that care to their patients.452

One of the other barriers to the delivery of a comprehensive palliative care system throughout Saudi Arabia and other Muslim majority countries (MMC) was identified by Gray, Ezzat, and Volker who pointed out that there is a deficit in terms of communication channels between physicians, patients, and their families in these countries.453 Whereas the relationship between physicians and patients in the United States and other Western countries is ideally and generally if not always based on truth telling – even at the cost of causing emotional distress in patients confronted with a poor prognosis – this is not the case in the MMC. Physicians often withhold bad news from patients and while family members may be given this news, the decision regarding revealing a poor prognosis or diagnosis in MMCs is generally left to the families themselves. The result of this communication insufficiency can be a very difficult conflict between a patient and the doctor, particularly with end of life decisions and palliative care.

It is the view of a number of researchers that the failure of Saudi physicians to be forthcoming is a contributing factor to the lack of palliative care use in the Kingdom. For example, Al-Shahri made note of the fact that Saudi doctors are figures of authority but Saudi patients and their families do not necessarily accept recommendations from physicians; the aforementioned attitude of leaving everything in the hands of a loving God tends to reduce the willingness of Saudi healthcare consumers to relay over much on what they perceive as the opinions of physicians.454 When communication breaks down in such situations, it becomes particularly difficult for patients and their families to make reasonably informed decisions about withholding care or using palliative care protocols to make the patient more comfortable.
This does tend to highlight the role played by culture in shaping palliative care and the development of palliative care services in Saudi Arabia. Researchers from many different countries have made it quite clear that culture is a significant determinant on many aspects of medical decisionmaking. Bullock, for example, demonstrated that culture in almost every societal environment is as powerful a determinant of end of life decisions as religion, individual beliefs and values, socioeconomic status, and perceived likelihood of an eminent demise.455

Other researchers have also explored this issue. When cultural misunderstandings occur, Saudi Arabian patients whose physicians are Western practitioners may believe that their cultural values are not being respected or perhaps or even understood. Given that a large number of the physicians practicing palliative care in the Kingdom are Western and not Arabic or Muslim, it is quite possible that resistance to palliative care is a form of cultural resistance as well. Many Muslims are particularly sensitive about the possibility that Westerners are imposing non-Islamic views and practices on them. This can certainly lead to a rejection of palliative care.456

This is readily apparent in the case of the Saudi reaction to opioid prescriptions. Usually, when an individual is facing a painful and potentially prolonged end of life stage, a physician will prescribe opioids and/or opiates, drugs that are not readily accessible in the Middle East due to regulatory as well as cultural obstacles that were described by Silberman and Jaloudi who stated that Saudi Arabia is one of a number of Muslim countries that have placed restrictions on the accessibility of such pharmaceuticals that impact not only on their manufacture in the Kingdom but also on imports.457

Also absent in Saudi Arabia is a national drug policy. The Kingdom does criminalize the use of certain substances including prescription medications such as opioids and opiates when they are abused. However, there is no consistent set of guidelines that directly relate to the
requirements for prescribing physicians with respect to levels of drugs that can be prescribed, the frequency of doses, and mandatory consent. This deficit certainly serves as a barrier to a more effective implementation of palliative care services.458

Palliative Care Fellow Mohammad Al Gamadi, a Saudi physician deeply committed to expanding palliative care services in Saudi Arabia, stated that:

“In the entire Kingdom we have only two or three palliative care units with very limited capacity and you can imagine the need with 2.2 million Saudis, this is apart from the other nationalities, so altogether there are approximately 30 million people. There is a huge need for inpatient, outpatient and homecare services so we have a long way to go.”459

Further, this physician argued that patients themselves are suffering as a consequence of the lack of an adequate nationwide palliative care effort. Al Gamadi said that none of the centers are actually providing palliative care which results in a situation in which people approach death in an ICU where they may suffer unnecessary pain and where their families may be under the misapprehension that their loved one would be receiving active care. The utilization of resources in this manner is seen by Al Gamadi as inappropriate and wasteful. He gives the example of adolescents who are ventilated and intubated for five or six years – long past the point where there is any legitimate benefits to such treatment and the likelihood that the patient will suffer unnecessarily from complications from these interventions.460

These comments position the Saudi palliative care issue in the context of unnecessary pain and suffering inflicted on vulnerable men, women and children at a time when physicians and families should be focused on relieving such conditions rather than prolonging them. Acknowledging the Islamic emphasis on the sanctity of life, coupled with the belief that all things which occur are known to Allah and are His will, does not necessarily mean that palliative
Saudi healthcare professionals are being challenged to develop strategies for including palliative care (as well as increased use of opiates and other pharmaceuticals) as part of the standard set of services offered to patients and their families.

Dr. Al Gamadi pointed out that one of the problems in the Kingdom is that there is no coordinated effort underway to provide domestic training for large numbers of palliative care specialists, including doctors as well as nurses and social workers. While it is true that at certain large regional hospitals there are programs offering palliative care, as noted above many of these programs are staffed by Western healthcare professionals. In order to address the needs for improved palliative care services this particular healthcare professional argues that the government must mandate the development of training programs for palliative care and also work with religious officials and leaders to educate and inform these key actors as to the necessity of such programming.

Palliative care is not limited to the elimination of physical pain, although this is certainly an important aspect of such care. Any number of researchers make the case that spiritual care is a vital component of a palliative care program that addresses the needs of the entire patient and not merely his or her physical requirements. In Saudi Arabia, spirituality emerges within the context of the specific practices of Islam. There is evidenced that palliative care programs have attempted to establish a harmonious relationship with Islamic culture.

Tayeb, et al, for example, reported that at the end of life stage, Saudi Arabians and other Muslims value the presence of friends and/or family members at the bedside where verses from the Qur’an are recited. Similarly, Muslims even as death approaches are concerned regarding issues of self-esteem and body image as well as family harmony.
Patients with end stage cancer are often the primary focus of palliative care programs in Saudi Arabia. The following figure depicts the incidence of this condition and services to illustrate the potential significance of such programming.

Cancer Statistics

Population in 2008: 25.2m
People newly diagnosed with cancer (excluding NMSC) / yr: 13,300
Age-standardised rate, incidence per 100,000 people/yr: 87.6
Risk of getting cancer before age 75: 8.9%
People dying from cancer /yr: 8,900

What these data indicate is that based on cancer alone, palliative care program deficits in Saudi Arabia are of enormous significance. When the increase in patients with this particular life-threatening and life-ending condition is coupled with the lack of formal programming and knowledge regarding such comfort care, the problem is surely highlighted.

Research by Gassan Abudari focused on some of the issues and challenges that are related to providing palliative care in Saudi Arabia, drawing on the perspective of nurses. This analyst also focused on the question of palliative care for cancer patients – perhaps the most numerous group of individuals that are likely to require assistance in coping with an end of life stage that is linked to extreme pain and suffering.466

At the major hospital in Riyadh, King Faisal Specialist Hospital and Research Centre, between 2007 and 2011, some 12,605 new cancer cases were admitted for care. Of that number, each year about 700 patients were seen by the hospital’s palliative care team. However, not all patients referred for palliative care at this institution actually participated in it. Abudari makes
In the case that a number of such patients ultimately rejected care recommendations and chose instead to be treated along traditional Saudi medical lines. This is problematic for any number of reasons. Specifically, it is problematic because it denies access to care that could ease the passage from life into death without violating any of the tenets of the Islamic faith.

Part of the problem identified in this context is that many attending physicians and residents at the major Saudi university affiliated hospitals including King Faisal Hospital and King Abdul-Aziz University Hospital have limited knowledge regarding the benefits of palliative care and are consequently reluctant to recommend it. They may further feel conflicted when families of dying patients who would benefit from palliative care express concerns regarding it or directly reject such a recommendation.467

A study undertaken by Aljuaid, Mannan, Chaudhry, Rawat, and Majeed sought to identify the key issues, problems, barriers, and challenges in relation to the quality of care in university hospitals in Saudi Arabia and to provide recommendations for improvement.468 These authors carried out a systematic search using five different databases for articles published between January of 2004 and January of 2005 that focused on the quality of healthcare in university hospitals in the Kingdom. Looking at a total of eight studies, the researchers found that there were a number of challenges which had not been addressed at these institutions which focused directly on overall quality issues. One of those challenges was limited emphasis on palliative care not only for end of life stages but throughout the course of a disease or treatment regimen.

Patient centered care in their view ought to include palliative care programs that assist patients in coping with the physical, psychological, emotional, and spiritual consequences of their presenting problems.469 The authors found little evidence that these institutions had
embraced the kind of palliative care ideology that is found in the United States. Resistance to palliative care was seen as an artifact of a lack of knowledge about such care and a failure to effectively educate physicians and nurses on this important issue.

A similar research effort to that of Abudari, et al was undertaken by Al Shaikh, Alkhodari, Sormunen, and Hilleras who conducted eight individual qualitative semi-structured interviews whose subjects were intensive care unit (ICU) nurses in Saudi Arabia. Results indicated that the palliative care concept was not well known to most ICU nurses even though they applied aspects of it in their daily work. Some nurses actually stated to the researchers that when they offered palliative care, they did so subconsciously but without reference to any specific set of protocols. They indicated that they provided supportive care to patients and their families but that often families asked for what nurses viewed as unnecessary treatments such as prolonged intubation or ventilation. The nurses called for improving the educational system in the Kingdom so that they would be better able to offer more effective care.

One area in which there is a very real need for improved palliative care in Saudi Arabia is pediatric and neonatal palliative care. Al Alaiyan and Al Hazzani pointed out that none of the neonatal intensive care units in Saudi Arabia had in fact initiated a neonatal program for palliative care. The reason for this deficit is the lack of knowledge of such programs and their benefits as well as a fear of being accused of heartlessness and cruelty by acknowledging that a child is in fact dying. Palliative care begins with the diagnosis of a life-threatening terminal condition and continues throughout the course of illness regardless of the outcome.

There is additionally no specific pediatric palliative care advocacy group or network in Saudi Arabia where the majority of patients receiving palliative care program services are adults with advanced cancer. The efforts undertaken by some healthcare providers to pursue staff
specialization in pediatric palliative care are very much still in their infancy. The problem in part is due to the fact that health policymakers have not given adequate attention to this pressing need. Some researchers take the position that while the adoption of palliative care friendly policies and improved access to essential medications are important steps in Saudi Arabia, the central step towards better development of palliative care may well be the training of health professionals.472

These, then, are the most significant issues directly impacting upon palliative care program delivery in Saudi Arabia. It is clear that when one compares the state of the palliative care programming available in Saudi Arabia to that of such programming in the United States, there are substantial differences to be observed. Even the influx of Western medical practitioners and Saudi nationals trained in Western institutions has not as yet succeeded in advancing palliative medicine to the extent that is clearly necessary. Aljawi and Harford note that a palliative care program must be based on a rational drug policy which includes ready access of suffering patients to opioids. While palliative care is much more than pain relief, it cannot be adequate if pain is not relieved and if the barriers to the rational use of opioid analgesics are not eliminated by government policies.473 As the next section of this chapter of the study will argue, the way forward in Saudi Arabia and elsewhere must be embraced at the highest levels of the government.

C. The Way Forward

The foregoing discussion highlights the reality of the palliative care situation in Saudi Arabia. As multiple researchers have affirmed, there is a very real deficit of such care services in the Kingdom as is the case in a number of other countries in the region. This includes low and middle-income countries. Aljawi and Harford note that while palliative care is widely recognized
among medical practitioners across the globe, it has yet to be fully accepted in a number of regions due to a combination of factors that must be identified as including religion, culture, government policy, and traditionalism.474

To address and reduce these barriers, a number of individual issues must be taken upon by policymakers in government and in the healthcare sector itself. Changes will need to be affected in the following areas:

- Laws and policies promulgated by the government and healthcare providers respectively.
- The knowledge, attitudes, and behaviors of medical practitioners.
- New regulatory systems impacting on the understanding of the proper use of opioids and opiates in treating pain and suffering.
- Enhanced understanding of the concept of palliative care on the part of religious leaders as well as among healthcare consumers and their families.
- New training for Saudi Arabian nationals who have not had previous exposure to the strategies, practices, and evidence based use of palliative care.
- The expansion of fellowship and other advanced opportunities for attending international conferences and workshops that are focused on palliative care.475

Clearly, there is a great deal for Saudi policymakers, healthcare professionals, and hospital administrators to learn from the elements of the United States palliative care system. A central feature in this system is pain management which is recognized as one of the most significant issues in end of life treatment.476

The primary objective of all palliative care programming is nothing more and nothing less than the quality of life of patients. This means that the management of physical pain sits at
the heart of such programming. Any palliative care programming that does not incorporate a strong emphasis on pain management cannot be considered to be adequate. In the United States and many other Western countries pain management via the careful administration of opioids and opiates is a medical specialty in and of itself. It is also a practice that is supported by a large body of evidence regarding its efficacy in not only reducing pain related to conditions such as cancer but also facilitating death with dignity and a sense of control.477

When it comes to pain management, the research leads inevitably to the conclusion that in Saudi Arabia the palliative care system is extremely constrained with regard to restrictions on access to opioids and opiates.478 Saudis must become more accepting of the recognition that managing pain through the use of such pharmaceuticals is not in any way antithetical to the belief that Allah does not give to any of His people suffering that cannot be endured or is not somehow a necessity. This particular belief appears on balance to be directly linked to the failure in many Muslim countries to allow adequate access to these particular medications. In fact, Aljawi and Harford assert that throughout the Middle East and North Africa and Sub-Saharan Africa and the Asia-Pacific region where Muslims tend to be concentrated, there are much more restrictive attitudes regarding the administration of opioids and opiates than in either Europe or the Americas.479

The healthcare system in Saudi Arabia through which palliative care is offered will be significantly if and when these particular drugs are made more accessible. In order for this to occur it will be necessary for medical practitioners to synthesis Islamic values with those of a Western medical system that is dominated by the belief that medical care should not only do no harm, it should also actively work to relieve suffering when this is possible. Many Westerners fail to understand how embedded in Islamic culture the values of Islam are and how spirituality
and religion in Muslim cultures are important coping mechanisms which directly impact on responsiveness to healthcare recommendations. Many patients who might benefit from opiate and opioid administration in Saudi Arabia need to be reassured that using such pharmaceutical preparations is not in fact antithetical to their faith and will not lead them into religious error.

In addition, the Saudi medical system of delivering palliative care would also benefit from the American system with regard to the kinds of relationships that are viewed as appropriate between physicians, patients, and family members. This report has highlighted the fact that physicians are not fully forthcoming in Saudi Arabia when it comes to informing patients or their families that no further treatment or interventions are indicated. Further, many Saudi healthcare consumers and their families are known to pressure for additional treatments which may have little or no benefit and may ultimately serve to prolong life at great physical and emotional cost to the patient.

Because this is the case, it is incumbent upon Saudi caregivers to become more open in terms of their communications with their patients and their patients’ families. While it is true that Saudis like many other Arabs tend to hold professionals such as doctors in high regard and to defer to them as figures of expertise and authority, it is also true that Saudi physicians do not want to unduly upset their patients and may consequently not communicate as freely or openly as is the custom in the United States. Here, training will be needed to reorient medical practitioners so that they will feel better able to inform their patients as to care options and the probability that any particular option will be successful. The experience in the United States is that a better-informed patient is able to make better decisions and the poorly informed patient is not likely to do so.
Of course, this particular challenge is best addressed within the specific cultural and religious context of Saudi Arabia. This issue will be discussed in depth in Chapter Six. Suffice it to say at this juncture, changing attitudes in the Kingdom will not be a simple or easy process and will certainly require the involvement of a large number of actors including those within the religious establishment.

Conclusions

This chapter of the study supports the conclusion that palliative care is a critical and integral component of the end of life care system and a component that is unfortunately not sufficiently addressed in the Saudi Arabian healthcare system. While strides forward have been made which bode well for continued improvement to the Saudi system, at the present time it is important to give more attention to further improvements in the national approach to palliative care.
Chapter Six

Withdrawing and Withholding Treatment: Comparison of the U.S. and Saudi Arabia

Introduction

Among the more emotionally charged decisions made within the healthcare setting regardless of the country or culture in which the healthcare institution is positioned, are decisions regarding withholding or withdrawing treatment. Such decisions generally occur in cases where the patient is experiencing a terminal illness or the end stages of a disease or trauma from which there is no recovery and which may not necessarily lead to a relatively quick termination of life.482 Such decisions are usually made in palliative care settings, in intensive or critical care units, or in the immediate aftermath of trauma.

In the United States and elsewhere it is argued that the principle of patient autonomy mandates that physicians be given consent by a patient or a responsible family member or designated individual with a power of attorney. Consent must be given for both administering or withholding and withdrawing treatment. In most cases, such decisions are not perceived as raising major challenges. However, in the end of life situation, decisions to withhold or withdraw treatment are accompanied by significant implications because they lead inevitably to the death of the patient.

Healthcare professionals define withholding and the withdrawal of life support as “a process through which various medical interventions are either not given to patients or removed from them with the expectation that the patients will die from their underlying illnesses.”483 Withholding and withdrawing practices occur in palliative care settings and are not inclusive of the denial of pharmaceutical preparations that diminish pain and suffering. Such practices tend to
consist of removing those devices or withholding those treatments that sustain and prolong or maintain life and without which life cannot continue.484

Patients may consider many life-sustaining treatments; in addition to cardiopulmonary resuscitation (CPR), options include elective intubation, mechanical ventilation, surgery, dialysis, blood transfusions, artificial nutrition and hydration, diagnostic tests, antibiotics, other medications and treatments, as well as future admissions to the hospital or to the intensive care unit. The treatment choices and the complexities increase as a patient's condition worsens. However, many patients who initially choose a do-not-resuscitate (DNR) order opt for progressively more restrictions as diseases progress. Although not using an intervention and withdrawing that intervention are ethically and legally equivalent, it is better to make these decisions ahead of time.485

Withholding and withdrawing as well as palliative care are supported by ethical principles of autonomy, beneficence and nonmaleficence. In the United States and in Saudi Arabia, both of which are the focus of this study, these ethical principles have a direct impact upon decisions regarding the withholding and withdrawal of life support systems and treatments. This chapter of the study first explores the broad ethical dimensions of withdrawing and withholding treatment. It then moves to a discussion of practices in the United States and in the Kingdom of Saudi Arabia. The Way Forward is considered with respect to what might occur in the Saudi Arabian healthcare environment.

A. Ethical Issues in Withholding and Withdrawing Treatment

Many analysts have commented that the tremendous advances occurring in medical science and related technologies have improved the ability of medical caregivers to prolong patient lives even when the patient is diagnosed with a probably terminal illness.486 New
treatments for even the most aggressive cancers can extend the life of an individual and provide for a viable quality of life. Nevertheless, there are some very significant limitations as to what can be done to prolong life while simultaneously providing the patient with an acceptable quality of life.

Recognition of such limitations has not only fostered an increase in withholding and withdrawing life support practices within palliative and other end of life care systems. It has also focused attention on ethical issues that naturally arise in such circumstances. Gedge, Giacomini, and Cook note that “contemporary ethical guidelines for critical care give ambiguous advice, largely because they focus on the moral equivalence of withdrawing and withholding care without confronting the very real differences regarding who is aware and informed of intervention options and how patient values are communicated and enacted.”

These are issues that introduce the question of physician obligations to their patients. Once the patient enters into the healthcare institution, the duty of care mandates that a physician take those actions that are reasonable to keep patients alive. Failing to act can subject the physician to criminal liability for any damages that might arise. That said, physicians also must make available to their patients or their patients’ representatives full information about interventions that are available and their potential effects, both positive and negative.

Richard J. Ackerman identified the basic concerns that enter into discussion when questions of withdrawing or withholding treatment are advanced, including such questions as: 1) Are physicians legally required to provide all life-sustaining measures possible?; 2) Are physicians legally required to provide all life-sustaining measures possible?; 3) Are you killing the patient when you remove the ventilator and treat the pain?; 4) Can the treatment of
symptoms constitute euthanasia?; and, 5) Is it illegal to prescribe large doses of opioids to relieve pain, breathlessness or other symptoms? 489

These questions and answers speak directly to the ethical issues that physicians and other caregivers must address when dealing with withholding or withdrawing treatment from the terminally ill patient. Ackerman noted that physicians must also work with patients and/or their family member or legal representatives to ascertain what the wishes and preferences of the patient are.490

Medical practitioners, according to Gedge, et al, at times withhold information about interventions that they judge are too futile to offer, thus retaining “greater decisionmaking burden and power and facing weaker obligations to secure consent from patients or proxies.”491 Withholding and withdrawing practices in general are viewed as ethical by physicians in those cases where medical treatment has proven to be futile. Treatments are considered to be futile when and if they do not offer patients any chance of surviving. In such circumstances, medical practitioners have no obligation to offer patients such treatment or to administer treatment that is both futile and burdensome.492

Because this is the case, practitioners cannot be held liable on the basis of duty to care when they fail to administer treatments or continue treatments that have definitively been proven to be futile. Researchers point out that from an ethical perspective, there is no meaningful difference between withholding and withdrawing treatment; most guidance documents described by Gedge, et al in a meta analysis of the literature on this issue reveal an emerging consensus on this question and indicate that the obligation of physicians is not to offer or provide futile treatment but to ensure that patients are informed adequately about their situation.493
This leads to ethical questions about withdrawing and withholding. Griffith argued that the ethical issues surrounding withholding and withdrawing treatment are substantive. First, the physician must be fully convinced that the patient is suffering from a terminal illness or disease or that death is relatively imminent and inevitable. Secondly, the physician must have reached a professional conclusion that the available treatments or interventions which could be given to the patient will neither prolong life nor improve the quality of life as the patient moves inexorably toward death. Third, the physician must have informed the patient and/or the patient’s significant others or designated decisionmakers that these circumstances exist. The information must be accompanied by an explanation of what effects withholding or withdrawing treatment will have on the patient. Fourth, consent must be obtained from the patient or the patient’s designated holder of a medical power of attorney. If the patient has a living will or a do not resuscitate order in place, this can be regarded as consent. Thus, both legally and ethically, a physician has no obligation to continue providing treatments that are futile.

In their study of 49 withholding and withdrawing guidance protocols, Gedge, et al found that 29 of these documents deal with the ethical equivalents of withholding versus withdrawing life support from acutely ill patients while 28 stated that they are ethically or legally equivalent actions. Nevertheless, these researchers found that many of these guidance documents indicate that there are important psychological or social differences between withholding and withdrawing, such as:

- Withdrawal of treatment may suggest patient abandonment.
- Withdrawal of treatment may be perceived as more obviously connected to a hastened death.
• Religious and secular ethical understandings of the difference between these two acts may differ and indicate a need for greater sensitivity in dealing with patients.

• Withholding treatment may strategically be useful in avoiding unnecessary or burdensome interventions.

• Withholding treatment may be viewed with suspicion by their patients or their families who have not come to terms with the full extent of the patients’ condition.

• Withholding may be easier for physicians than withdrawing treatment because it is perceived as a passive rather than more aggressive act.

Other issues that are central to the ethical questions surrounding withdrawal and withholding treatment address questions of benefit and futility. Patient benefits play a central role in ethical responses to patient needs and medical interventions. Orlowski, Collins, and Cancian stated that “if a treatment is clearly futile in the sense that it will not achieve its physiological objective and so offered no benefit to the patient, there is no obligation to provide treatment.”497 Futile treatments are those, therefore, that offer no physiological benefit.

A broader professional standard than one based on strict futility or physiological futility suggests that “if general medical opinion considers a particular treatment as futile (not altering the patient’s immediate survival nor offering any advantage over alternative treatments) then this alternative need not be performed or even discussed with the patient or his surrogate.”498 While it can be argued that assessments of benefit are essentially subjective, it should be acknowledged that more often than not it is or should be up to the patient to determine whether or not even a small physiological or psychological improvement in one’s condition is sufficiently beneficial to justify it.
Standards that come into play in this context as described by Gedge, et al include the patient’s quality of life, the best interests of the patients, and the proportionality standard. Decisional authority is also critical with most medical systems placing the patient and his or her needs and interests as superior to those of the physician. The entire question becomes problematic when the patient is unable to participate in such decisionmaking and does not have a designated holder of a medical power of attorney or a living will. Incapable and vulnerable patients include those who have no capacity to give informed decisions on withholding and withdrawing treatment. These patients may include children, mentally incapacitated adults, and unconscious adults.

Here, both legal as well as ethical interests arise. The principles of informed consent and informed refusal are rooted in both ethics and the common law. Together, they hold that “treatment may not be initiated without the approval of patients or their surrogates excepting in emergency situations, and that patients or surrogates may refuse any or all therapies.” Surrogate decisionmakers are recognized in the United States and elsewhere as legitimately empowered to make decisions on behalf of vulnerable or incapacitated patients. Usually, such decisionmakers are drawn from the families of the patient or decisions are made by a court appointed legal guardian when no family member or designated decisionmaker exists.

The key here as described by Willmott, White, and Downie is that caregivers must have determined that treatment if continued or offered would be futile and that it would not provide any meaningful benefits to the patient. It is incumbent upon the physician to make sure that either the patient if he or she is capable of participating or a designated representative understand that no benefits of any significance would be generated by continuing or offering treatment.
Here again, one must acknowledge that patient preference plays a role in determining whether or not withdrawal or withholding should occur. Using a due process model in the view of Gedge, et al allows for an opportunity to create a fully inclusive decisionmaking environment. Clinical guidance documents are therefore of enormous significance in medical care settings. These documents can serve to establish the broad parameters under which withdrawing and withholding of treatment is to be viewed as an option. They can and should clearly identify what is meant by futility and what the respective roles are of all actors in these scenarios. They do serve as these analysts note to protect physicians and their affiliated institutions against legal liability for withdrawing or withholding treatment. They also serve to provide patients and their family members or guardians with protections that serve their interests.502

The eight step protocol for use in discussions of withdrawing or withholding treatment consists of: 1) being familiar with institutional policies and state laws; 2) choosing an appropriate setting for the discussion; 3) ensuring that the patients and his or her family understand the issue thoroughly; 4) discussing the values of the patient and the specific goals of critical care; 5) establishing the context for the discussion; 6) discussing specific treatment preferences; 7) responding to emotions expressed in the discussion; and 8) establish and implement the plan for care.503 These broad guidelines are, perhaps, easier to list than to follow. There is no denying the intense emotionality of decisions centered on withholding or withdrawing treatment.

Also of significance ethically are the criteria that are used to classify treatment as either ordinary or extraordinary. Physicians are permitted to withdraw treatment when the patient’s condition is proven to be irreversible, but they are expected to continue to administer those types of care identified as ordinary. This includes feeding and hydrating a patient. Willmott, et al
make note of the fact that there are ethical arguments that develop when physicians attempt to
deﬁne an intervention as ordinary versus extraordinary.504

While feeding and hydrating may be perceived as ordinary interventions and not as
extraordinary ones, even these fairly standard actions become problematic when technology is
required to provide food or hydration and when the patient either refuses such interventions or
has indicated that he or she does not want them. In the case in the United States of Karen Ann
Quinlan, a patient refused such interventions including mechanical ventilation but although
Quinlan herself was in a vegetative state and was unable to exercise that right directly, the courts
held that her parents could act on her behalf.505

A similar case, Barber v. Superior Court, heard by the California Court of Appeals, is
important in this context. Physicians who were charged with murder were convicted by the
lower courts, but on appeal it was held that these physicians had not committed an unlawful act
when, with permission from a patient’s family, they withdrew nutrition and hydration from a
comatose patient.506 The principles represented in these two cases are widely accepted but
statutory and case law regarding the limitations of life sustaining treatment vary from state to
state and, as signiﬁcantly, from country to country.

There are a number of considerations that medical caregivers say should be examined
when initiating, withdrawing, or withholding artiﬁcial hydration and nutrition. When initiating
these interventions, it is important that an informed patient or decisionmaker choose the option
that reﬂects their personal values particularly when their primary goal is to maximize the
quantity of life and when the patient is either stable or improving which means that the
intervention has a reasonable chance of reaching the goals of the patient. Withdrawing or
withholding becomes an option when either the patient or a designated decisionmaker who has
been informed thoroughly about the prognosis of the patient decides against an intervention because they either seek palliation of symptoms or when the intervention is bound to fail. Further, when patients have either end stage organ failure or other diseases, are profoundly impaired, when the quality of life as defined by the patient is poor, and when risks exceed benefits it becomes reasonable to withdraw or withhold artificial hydration or nutrition.\textsuperscript{507}

This is a fairly substantial listing of the circumstances in which either offering or withholding/withdrawing hydration or nutrition may be indicated. It is, said Ackerman, left to the professional judgment of a physician and the preferences of the patient or the patient’s legal representative when each situation should be addressed.\textsuperscript{508}

It should be noted that laws in many different societies have been crafted to permit withdrawal of extraordinary care or treatment while affirming the necessity of maintaining ordinary care.\textsuperscript{509} An important case in the United States that was centered exactly on this issue was that of Karen Ann Quinlan, and more recently, the case of Teresa Schiavo in which the husband and legal guardian of a comatose women in a vegetative state for a prolonged period of time sought to have a feeding tube removed. The parents of the women objected. These cases are significant in light of the fact that determining when even ordinary treatments are being considered, there can be disagreement between key actors as to the best interests of the patient.

The ethical issues raised herein speak to questions of withdrawing and withholding treatment in all societies. However, it should be noted as has been stressed herein, that there are substantive cultural and national variations in terms of the ethical approach to withholding and withdrawing treatment for terminally ill individuals.\textsuperscript{510} The next sections of this chapter will discuss withholding and witholding practices first, in the United States and secondly, in Saudi
B. Withholding/Withdrawing Practices in the United States

Withholding and withdrawing life support practices are common across the United States in all varieties of end of life care settings. Much of the discussion in the preceding section of this chapter is based upon assessments of the response of interested stakeholders in the United States to this issue. The most significant principle upon which decisions justifying withdrawing or withholding of futile treatment in the United States arise from principles of patient autonomy, imperatives for consent, definitions of futility, and the subjective evaluation of and submission to benefits and burdens of life support in critical care settings.511

In the United States and other Anglo-American jurisdictions, the right of a patient to unequivocally refuse medical treatment is well established and justified by the principle of autonomy. According to this principle, medical practitioners in the United States believe that people have a right to self-governance and to determine what will happen to their bodies. The right to refuse treatment places a recognized limit on interventions by doctors who are required to respect refusals even against their own best clinical judgement and if the life of the patient is at risk as a result.

Further, “patients may thus insist that treatment not be given or be withdrawn, and doctors may be expected to comply. However, the mandate of doctors to respect patient refusals has not been taken to extend to an obligation to secure patient consent to the withholding of treatment.”512 In most cases, the patient’s right to self-determination outweighs any other
interest. Under the law, respect for patient autonomy is seen as bestowing a negative right, a right to non-interference. A more positive interpretation of autonomy would arguably entitle everyone to every requested medical intervention or treatment regardless of medical advisability or competing claims for limited or scarce resources. Consequently, physicians in the United States who value the ethical duty to provide appropriate care which is derived from the principle of beneficence and professional accountability, often run up against patient autonomy.

Gallagher does point out that personal autonomy must not be and is not in the United States the overriding principle in withholding or withdrawing decisions because this principle alone does not have the ability to address all moral concerns. While important in the United States, the principle of autonomy is not totally binding and cannot supersede all principles in all situations. Because this is the case, physicians are often compelled by the law and by their ethical codes to administer treatment in cases where a viable treatment is available.

This seems to particularly be the case when the disease from which the patient is suffering is infectious. The purpose of this particular prohibition is to ensure that an infectious disease is aggressively addressed. The goal is to prevent the spread of infection which occurs all too frequently in the confined environment of a hospital or other healthcare institution. Patients with an infectious disease whose condition is terminal may be under legal obligations to accept treatment even if that treatment will not result in any improvement in their own condition.

Another concern in the United States centers on questions regarding the integrity of a physician and the standard of practice in the medical profession or specialty. According to Gedge, et al, some analysts “deny that physician integrity requires limiting patient autonomy to refusals and argue that patient consent should be required for both withholding and withdrawing
treatment at the end of life.”515 The fundamental point is that there are likely to be conflicts between patient autonomy and the integrity of the physician.

In the United States, the case of *U.S. v. George* was heard by the Supreme Court which ruled essentially that patients should not be able to dictate the course of their treatment when doing so requires a physician to ignore their own conscience.516 In this particular ruling, the Supreme Court held that when a hospital is an involuntary host to the patient, physicians should not be required to ignore their own conscience. The question is whether or not withdrawing or withholding treatment is viewed by the physician as antithetical to the often conflicting ethical principles of non-maleficence (do no harm) and justice (distribute scarce resources fairly).

The positive obligations that are attached to being a physician do not derive from patient autonomy but rather these principles and the principle of beneficence and professional accountability. The principle of non-maleficence is often used to justify both withholding and withdrawing treatment. This principle essentially requires that any harm done to a patient must have a good reason behind it. Administering a particularly aggressive treatment when it is clear that the option is futile is recognized in the United States as violating the principle of non-maleficence.517

American courts have consistently upheld the right of patients to refuse treatment, using the right of religious freedom as a justification for such a decision. A New York court, for example, upheld the decision to refuse a blood transfusion procedure by a 23 year-old woman. She had asserted that submitting to the transfusion would violate her religious beliefs even though she was certainly aware that refusing the transfusion placed her life in jeopardy.518

A critical case in this context is that of *Cruzan v. Director, Missouri Department of Health*.519 In this case, parents requested the removal of a feeding tube from their vegetative
daughter. The family lived in Missouri, a state requiring specific evidence that an incompetent would want treatment withdrawn. In making its decision, the Supreme Court affirmed that Missouri and other states could require clear and convincing evidence of patients’ wishes. This potentially limits the role of surrogates in making decisions for incompetent patients who do not have advanced directives. At the same time, however, the Court did acknowledge what has become a fundamental element in American practice and policy regarding withdrawing and withholding treatment - the principle that a competent person has the right to forego even ordinary treatment such as nutrition and hydration because of a liberty interest that is protected under the Fourteenth Amendment to the Constitution.

However, while the Supreme Court did approve the withdrawing and withholding of life support under the principle of informed refusal in the *Cruzan* decision, it did not take up the question of futility. Luce and Alpers state that “futility is difficult to quantify…. The concept may also mean different things to physicians than it does to patients and their surrogates. Nevertheless, physicians frequently cite futility in recommending that life sustaining therapy be foregone.”

Some physicians in the United States, according to research by Luce and Alpers, have actually acknowledged that they have unilaterally withheld treatment or withdrawn life support they considered to be futile without informing patients or their surrogates or despite their objections. In the United States there is a history of legal cases involving futility. The courts have almost uniformly tended to order continued treatment when asked to resolve disputes between families who want treatment to continue and physicians who oppose it. The courts have also become unwilling to appear to cause the death of a patient as was seen in the case of Baby K. In that case, the Court was asked to approve in advance a physician’s decision to withhold
life sustaining treatment and refused to do so. What this suggests is that the Courts are often reluctant to interfere in this kind of decision-making. When they engage in such decisions, they seem to come down on the side of sustaining rather than eliminating treatment.

At the same time, the courts have also been reluctant to take action against or punish physicians who carefully and within the parameters of professional standards refuse to provide treatment they consider to be inappropriate. Here, the only clear legal rule on futile or nonbeneficial treatment derives from the malpractice test which measures a physician’s decisions against the appropriate standard of medical care, requiring that any substandard care cause the patient injury. This issue was raised in the Gilgunn case in which a jury in Massachusetts refused to impose liability on a hospital or the physicians practicing there after they removed the ventilator from a patient despite objections from one of the patient’s daughters.523

In essence, the Gilgunn case seems to represent a trend in futility cases. Physicians are able to obtain better legal outcomes when they refuse to provide nonbeneficial treatment and defend decisions as consistent with professional standards. This appears to be a better approach than seeking permission in advance to withhold care. This introduces the question of how withholding and withdrawing practices can be justified by the quality of life perspective of healthcare.

Previously, in the United States, the effectiveness of healthcare has been measured by issues related to reduction and disease and the extension of life. Medical caregivers focused on curing rather than caring per se and in this approach, withdrawing or withholding treatment is conceived of as an act of abandonment in which the patient is not well served by the physician.524 Today, however, the medical profession conceives of its primary objective as pursuing options that are beneficial to the patient. To justify a treatment or intervention it
becomes necessary to determine that it will provide a positive benefit to the patient. If this benefit is unlikely to be forthcoming, the treatment itself is no longer justifiable. Rather than abandoning the patient, withholding or withdrawing treatment represents a change in the approach taken to care in the best interest of the patient.  

Hester noted that many American doctors are guided by Utilitarian ethics in which practices of withholding or withdrawing treatment are based on issues regarding the effective utilization of resources. Utilitarian ethics are based upon the so called Hedonic Calculus. This is a mathematical approach to assessing the benefits to be derived from a particular act not only in terms of their immediacy but in terms of the extent to which these benefits can be enjoyed by many rather than a few individuals. At its core, Utilitarianism calls for doing those things that will provide the greatest benefit for the greatest number of individuals.

The majority of Utilitarian physicians make the case that treatment for end of life patients is extremely costly. Many end of life treatments and interventions are rare and should not, therefore, be wasted. Such treatments should be used in those cases where they are most likely to have substantive or longer term positive benefits. In the American healthcare system which lacks a universal system of either delivery or compensation, there is always the possibility that patients with deep pockets will be able to acquire medical interventions and treatments that do not reflect an efficient utilization of resources. Simultaneously, patients lacking the financial capacity to acquire such treatments may not receive them or may have them withheld. This is an issue that is certainly troubling to American medical institutions which must nevertheless give attention to the constraints under which they operate.

One should also recognize that in the United States, physicians often choose to withdraw or withhold treatment because it is seen as having side effects which can cause additional
problems for the terminally ill patient. If a particular treatment is accompanied by the possibility of negative effects and not linked specifically to any benefit, the consensus is that patients should not be subjected to such treatment.\textsuperscript{528}

Reference has been made herein to the situation of unconscious adults, patients who are comatose or in a persistent vegetative state. Such patients present very real challenges for physicians, particularly in the absence of advance directives or durable powers or attorney. These instruments, which are increasingly common in use in the United States and other Anglo-Western countries, allow patients to identify what treatments or interventions they will and will not accept and the circumstances under which they would choose to accept or reject such care. The incapacitated adult with an advance directive possesses what American physicians see as sufficient autonomy on which care decisions can be made.\textsuperscript{529}

Advance directives are also applicable when the patient is proven to be mentally rather than or in addition to physically incapacitated. Durable powers of attorney are instruments that allow competent adults to select an individual who is then authorized to make medical decisions on their behalf should they become incapacitated physically or mentally. Gedge, et al make note of the fact that these instruments represent decisional authority that physicians must view as normative.\textsuperscript{530}

No discussion of this issue in the U.S. would be complete without reference to the case of Terry Schiavo. Schiavo lived in a vegetative state for over ten years due to a cardiac arrest. After about eight years, her husband, the respondent, Michael Schiavo petitioned the court to authorize the termination of life-prolonging procedures. The court granted the husband’s request and the nutrition and hydration tube that had been prolonging Shiva’s life was removed. Six days later, the Florida legislature enacted a statute enabling the Governor to issue a one-time stay to prevent
the withholding of nutrition and hydration from a patient if the patient had no advance directive, the court the patient to be in a persistent vegetative state, the patient has had nutrition and hydration withheld, and a member of that patient’s family has challenged the withholding of nutrition and hydration.\textsuperscript{531}

Florida governor Jeb Bush intervened. The Legislature enacted the law giving the Governor the power to reinsert a feeding tube which a court had given another person the power to remove. This act is a violation of the separation of the powers of the executive, judicial, and legislative branches. Furthermore, the statute delegates legislative power to the Governor because it does not set forth criteria for lifting the stay, it does not say how long the stay should be issued, and it gives the Governor absolute discretion to decide when to issue the stay and went to lift it.\textsuperscript{532} Despite the intervention, the tube was eventually removed and Schiavo died.

In the case of children, American law currently prohibits withdrawing ordinary care options including hydration and feeding, pain relief, and hygiene care. The Child Abuse Amendments Act of 1984, which remains in force more than 30 years after its passage, characterizes the withdrawal of these types of ordinary care as equal to child neglect or child abuse.\textsuperscript{533} Parents facing situations in which their minor child is diagnosed as terminally ill are permitted to participate in decisionmaking with respect to withholding or withdrawing extraordinary interventions. For example, parents may agree that maintaining a child on a ventilator is futile and the tubing can therefore be withdrawn without the risk of legal charges against either the parents or the institution and its physicians.

In the United States, as has been suggested herein, the rules impacting upon this kind of decisionmaking vary from one state to another and in some instances, from one jurisdiction in a state to another. This is a particularly significant question when the patient has been ruled to be
incompetent either because of physical incapacity or mental incompetence and inability to make informed decisions. Some jurisdictions in the United States allow the families or legally appointed guardians of these patients to make decisions without any requirement of court intervention. Others mandate that a hospital or other care institution must receive court approval before withdrawing or withholding life support systems. Hospitals tend, for the most part, to err on the side of caution to avoid any potential legal consequences and to eliminate charges that unsolicited physician assisted suicide has occurred.

What, then, can be concluded regarding policies and practices in the United States about withdrawing and withholding treatment from the terminally ill patient? This discussion leads to the conclusion that key actors in the American healthcare system remain somewhat divided on questions of withdrawing and withholding treatment. Multiple legal cases have been brought that seek to establish the conditions under which withdrawing or withholding treatment are acceptable and even desirable or beneficial to patients. These cases are not necessarily definitive and it is highly probable that it will be necessary for courts to revisit these issues to respond to specific concerns.

The next section of this chapter will consider withholding and withdrawing practices in Saudi Arabia, a country in which the prevailing legal and ethical norms tend to be quite different from those in the United States and other Western nations. Even though this is the case, and even though medical care in Saudi Arabia is normed by religious belief and value systems, there are some similarities between the two countries.
C. Withdrawing and Withholding Practices in Saudi Arabia

Muslims believe in death as depicted in the Qur’an: “every soul shall have a taste of death.” Muslims also submit to the doctrine that no soul dies except by the permission of Allah, demonstrating Muslim belief that it is only God who determines the life and death of an individual. Further, Islam holds human life sacred and according to Takouri and Halwani, “nobody on earth can end it except in situations of punishing somebody purposely committing murder or spreading mischief on earth.”

For Muslims, the most contentious ethical issue related to the subject of withholding or withdrawing treatment is the view that a patient has a right to die. Western societies, including the United States, are generally cognizant of both the right to life and the right to die under certain circumstances. This is readily apparent in the widespread Western support for such tools as the DNR instruction and guidance on those occasions when withdrawing or withholding medical treatment is to be viewed as acceptable.

The case is different in Saudi Arabia where even extraordinary treatments and interventions are often provided long beyond the point when they are meaningful. Additionally, one of the biggest ethical challenges in Saudi Arabia centers on withdrawing or withholding artificial nutrition and hydration from terminally ill patients. Alsolamy notes that the literature provides relatively little information about Islamic beliefs, attitudes, and laws that are related to these challenges. This in and of itself complicates the responsibilities of physicians, who, as has been noted elsewhere in this discussion, enjoy a more authoritarian and paternalistic role in Islamic medical settings than is the case in the United States and other Western countries.

Physicians in Islamic culture are under no obligation to take actions that prolong the dying process and it is believed by most Muslim physicians that the patient has a right to express
their views on end of life care through such mechanisms as advance directives and standing DNR orders. According to Gouida, et al, the Islamic Research and Ifta has proclaimed that life supporting systems such as ventilation may be withdrawn when three trustworthy and knowledgeable physicians jointly agree that the condition of the patient is hopeless and that continued treatment and intervention will essentially be futile.  

The Islamic Research and Ifta’s verdict on the legitimacy of the DNR has served to drastically reduce the total number of patients in the Kingdom who are subject to futile treatment procedures. Many believe that this verdict has also served to promote the efficient utilization of intensive care resources which are less readily available in the Kingdom than they are in many Western countries. This is particularly the case in rural or non-urban areas in Saudi Arabia. In light of the fact that most of the state of the art ICU programs or palliative care providers are located in major Saudi Arabian cities, this issue is particularly critical.  

There are downsides to the policy requiring that three physicians agree that the patient’s condition is hopeless and it would therefore be ethically appropriate to withhold or withdraw treatment that would be essentially futile. Most significant are the following issues:

- The policy does not provide any meaningful involvement of the family of the terminally ill individual in the decision to withdraw or withhold treatment.
- Neither the patient if he or she is competent, nor the family are often educated fully as to the rationale for the decision to withdraw or withhold treatment.
- Ensuring that three sufficiently trustworthy and knowledgeable physicians agree with one another complicates the process and also serves to reinforce
the image of the system as authoritarian and paternalistic.

- Finally, the policy relies largely on principles of proportionality rather than patient autonomy which sits at the heart of the Western approach to the issue.542

These concerns serve to illustrate some of the critical differences between practices of withholding and withdrawing treatment when the United States and Saudi Arabia are compared.

Two important studies of Islamic medical end of life care were identified in the literature and both serve herein to describe how physicians in Saudi Arabia approach this particular issue. Al-Dorzi, et al employed a Web-based survey of physicians who were working at four different hospitals in the Kingdom, focusing on issues regarding withholding and withdrawing life support. The survey, which was developed specifically for this study, included general information about the participants themselves, general questions about end of life care, and questions about care guidelines for a terminally ill patient who deteriorated during a hospital stay.543

Most responses were on a five-point Likert scale and the instrument was validated, subjected to a pilot study, and then forwarded via email to physicians from four different hospitals through their department heads. Multivariate regression analysis was used by the researchers to study the factors that were associated end of life decisions with length of clinical experience, gender, Saudi nationality, consultants versus others, Western trained versus others, intensive care specialists versus others, and religiosity. Data were analyzed by means of the Statistical Package for the Social Sciences.544

The researchers identified a sample of 92 physicians with an average of 37 years (plus or minus eight years). Clinical experience of 11 years on average (plus or minus eight years), and
essentially multinational with 56 percent of the sample identified as Saudi, 25 percent as Middle Eastern, and five percent Western. Males comprised 86 percent of the sample while 41 percent were consultants rather than primary care physicians. A total of 34 percent of the participants had been trained in the West while 21 percent were specialists in intensive care. Median perceived religiosity was 7/10 with the majority of subjects identifying themselves as Muslim.\textsuperscript{545}

There was significant disagreement among the subjects as to the definition of the DNR order, with respondents expressing the following views of what it entails:

- 43 percent perceived it as prohibiting cardiopulmonary resuscitation (CPR).
- 48 percent perceived it as no CPR and limitation of therapy.
- 9 percent said that it called solely for comfort care.

More respondents indicated that they would never withdraw than would never withhold treatment from any patient, 35 percent versus 24 percent respectively. Multivariate analysis indicated that acceptance of life support withholding was associated with clinical experience and Saudi physicians were more likely to reject life support withdrawal while intensivists were more likely to accept it. Many respondents indicated that they would provide hemodialysis to a terminally patient but only 14 percent indicated they would perform CPR.\textsuperscript{546}

The most important factors identified by these physicians with respect to making end of life decisions were patients’ functional status, disease prognosis, and family wishes. It was concluded by Al-Dorzi, et al, that there is significant variation in the opinions of physicians working in Saudi Arabia working on end of life care in general. It seems that these subjects found withholding life support to be more acceptable than withdrawing such support. This study did not indicate that doctors practicing in Saudi Arabia were completely opposed to withdrawing
treatment but rather that such treatment should be carefully considered when it becomes necessary to determine what should be offered to patients as they approach the end of life.\textsuperscript{547}

A second study of significance is also worth exploring in further depth herein. Takouri and Halwani conducted a search of regional and international literature regarding policy and procedures on DNR practices in order to assess the overall state of such practices in Arabic and Islamic ICUs. They identified 138 books and articles available in 2007 using the general keywords Do Not Resuscitate in the Google Scholar database. Of that total, 32 were relevant to guidelines. Twelve articles dealt with research and one article addressed the issue of no code guidelines incorporated in optimizing ICU usage in Saudi Arabia.\textsuperscript{548}

These researchers emphasized the relationship between Islam and the DNR in their analysis, noting that withholding medical therapy at the end of life is widely accepted in many countries around the world on medical, legal, ethical, and moral grounds. They made reference to the fact that Islamic religion has been interpreted in this instance by the Presidency of the Administration of Islamic Research and Ifta in Riyadh. In this group’s Fatwa No. 12086 issued on 30.6.1409 (Hijra) (1988 AD) which states: “if three knowledgeable and trustworthy physicians agree that the patient condition is hopeless, the life supporting machines can be withheld or withdrawn. The family members’ opinion is not included in decisionmaking as they are unqualified to make such decisions.”\textsuperscript{549}

Based on this fatwa, many Saudi Arabian hospitals have implemented the No Code policy which is written to delineate the meaning and scope of a DNR order, determine the condition of a patient in which a DNR order is applicable, and determine who decides and approves the DNR order. Most such policies stipulate differences between basic life support from advanced life support, introducing questions of nutrition and hydration versus invasive
medications. These policies are generally applicable to both adult and pediatric patients and to the ICUs as well as wards of hospitals.550

These policies generally call for using CPR for victims of sudden cardiac or respiratory arrest with reversible causes when the treatment carries a reasonable possibility of remission of symptoms and the restoration of the patient to an acceptable functional existence rather than a biologically vegetative existence. Such conditions include: drowning and near drowning, suffocation, electric shock, lightning strikes, untoward effects of drugs, anesthetic accidents and surgical complications, acute myocardial infarction, heart block, and malignant arrhythmias. Physicians are advised to follow the principle of acting first and evaluating later.551

These guidelines are fairly detailed with respect to those terminal or untreatable chronic diseases that are associated with an extremely low chance of survival where a DNR should be applicable. These cases include cancer, multi-organ failure, demonstrable brain damage or brain death, advanced pulmonary diseases, inoperable congenital heart disease, fatal chromosomal anomalies, and neuromuscular diseases, and Werding Hoffman disease Spinal muscular atrophy type I. It is still necessary according to these guidelines for a team of physicians led by a consultant to identify critically ill patients as well as those whose condition leads to this status to determine those for whom CPR is inappropriate. A departmental committee must be convened to consider the DNR and when CPR has no potential benefit, at least two consulting physicians, both of whom are Muslim, must agree on the diagnosis.552

It is only after the physicians have achieved consensus on withdrawing or withholding treatment via the DNR that the family of the patient is informed with the goal of obtaining full approval. The question here, of course, is whether or not this set of practices called for by Fatwa No. 12086 exhibits sufficient respect for patient autonomy and the rights of patients and their
family members to play a normative role in end of life decisionmaking. On balance, this study serves to demonstrate that in Islamic care settings, the burden of decisionmaking is placed almost exclusively on physicians to the potential detriment of families and patients themselves.

This particular study as well as others emphasizes the underpinning cultural and religious issues and traditions that are operative in cases where a patient faces the end of life. As noted above, Islamic religious belief argues against ending human life except in cases where it is necessary to punish wrongdoers. Physicians who are extremely religious are likely to be of the opinion that withdrawing or withholding treatment even from the terminally ill patient is antithetical to their Islamic faith. Further given according to Al Husseini, is the fact that most of the hospitals and other caregiving institutions in Saudi Arabia have a strong orientation toward conservative interpretations of Islam.

What this means in essence is that many physicians in Saudi Arabia are likely to err on the side of caution and to continue offering or providing treatment far longer than physicians are generally likely to do in Western countries. Saudis take the view that the ethical imperatives of their faith take precedence over questions such as the distribution of resources and futility. Further, even among physicians in Saudi Arabia, there is likely to be poor understanding of palliative care and of the differences between withholding or withdrawing extraordinary versus ordinary treatments and interventions.

A study by Aljohaney and Bawazir sought to analyze perceptions of internal medicine residents in the Western region of Saudi Arabia about DNR orders. The goal of the study was to identify knowledge deficits that would be addressed in future training programs for physicians. A 16-question survey developed by the researchers was distributed to residents in Taif, Medinah, Makah, and Jeddah by means of surveymonkey.com. A total of 364 residents were asked to
participate. Of that population, 157 completed the questionnaire, resulting in a 43 percent response rate.\textsuperscript{555}

Of the sample, most or 66 percent indicated that they held end of life care discussions with patients and family or surrogate decisionmakers. Most residents (about half or 51.9 percent) indicated that they were relatively comfortable during such discussions and that they nevertheless felt that they would benefit from additional educational programs that specifically address issues related to DNR discussions. The researchers concluded that their study highlights the need for a structured curriculum to teach issues such as DNR orders to residents in the Saudi Arabian medical system.\textsuperscript{556}

This is one of the critical issues that tends to differentiate the Saudi and American healthcare systems. In the latter, the DNR is a well-established practice and one that along with other relevant end of life issues is thoroughly integrated into medical school curriculum. This is not the case in Saudi Arabia or, for that matter, in any number of Middle Eastern countries where Islam plays a significant role in determining what does and does not occur in medical practice.\textsuperscript{557}

The study of palliative cancer care in several Middle Eastern countries conducted by Silbermann, et al was quite revealing in this context because it demonstrated that there are many cultural barriers to the delivery of palliative care in these countries because people associate such care with giving up on life rather than providing quality of life when an individual is suffering a terminal illness.\textsuperscript{558} Training issues were identified by these analysts as substantive throughout the Middle East where cultural and religious traditions have combined to create an environment in which discussion of withholding and withdrawing treatment inevitably are linked to religious as opposed to essentially ethical norms.
One can certainly make note of the fact that in the largely Judeo-Christian cultures of Western countries, no single religion sits at the core of medical ethics decisionmaking.\textsuperscript{559} Certainly, Western medical ethics are grounded in religious norms, values, and beliefs but they are not subject to oversight by theologians. This is the exact opposite of the case in Saudi Arabia as the fact that Islamic religious leaders have determined the policies that will be maintained in hospitals with respect to caring for the terminally ill.

From the perspective of Islam, the rules governing the care of terminally ill patients are derived from the principles that injury and harm should be prevented or avoided. Thus, the hastening of death by the withdrawal of what could be arguably identified as ordinary care in the form of nutrition and hydration is forbidden. Nutritional support is considered to be basic care and not medical treatment, and therefore it imposes on physicians the obligation to provide these fundamental necessities to the dying person unless to do so would shorten life, cause more harm than benefit, or be contrary to an advanced directive that is consistent with Islamic law.\textsuperscript{560}

When decisions about withdrawing or withholding artificial nutrition and hydration from the terminally ill patient are made in Muslim healthcare settings, informed consent from a guardian or the patient is required along with consideration of the clinical context of minimizing harm to the patient. In theory if not necessarily always in practice, Alsolamy states that this informed consent includes input from a competent or capable patient and his or her family members. In practice, however, more often than not this decision is reached by healthcare professionals and religious scholars with relatively minimal input from the individuals who are most directly and immediately impacted by the decision.\textsuperscript{561}

Here, the issue of futility does take on significance. Artificial nutrition and hydration can under certain circumstances reduce the quality of life and ultimately be futile. They can harm a
terminally ill patient who might experience complications such as pneumonia, nausea, diarrhea, dyspnea, or hypervolemia. These side effects must be taken into account when Muslim physicians make decisions regarding withholding or withdrawing artificial nutrition and hydration.562

Earlier chapters in this study focused on the religious aspects of end of life care in Saudi Arabia and other Muslim countries. The influence of religion in this context cannot be overemphasized. Muslims do accept the inevitability of death and believe that when death occurs it always does so with the will of Allah and it is only Allah who possesses the right of decision regarding the termination of this life. Patience, endurance, and suffering as well as pain are all conceptualized as having value within the Islamic faith. Patients in Islamic care settings are often encouraged to accept and to endure suffering.563

The Qur’an states that pain is a kind of trial in which a believer is given an opportunity to confirm their spiritual adherence to Islam: “surely, we will try you with something of fear and hunger and diminution of goods and lives and fruits; yet give good tidings to the patient, who, when a misfortune befalls them, say ‘surely we belong to God, and to him we return’; upon those rest blessings and mercy from their Lord, and those; they are the truly guided.”564

Pain therefore functions as a moral and spiritual aspect of living and further allows an individual to experience self-purification. Some Muslims interpret this part of the Qur’an as calling for an elimination of the use of opioids and other analgesics in the treatment of pain at the end of life. Others disagree and contend that as long as such treatments are not designed to shorten the life of the patient, they should be fully available if the patient desires them.565

Muslim scholars are increasingly willing to recognize the importance of decisions that are derived from specific human conditions as an equally valid source for social ethics in Islam as
are scriptural sources such as the Qur’an and the Sunnah. That said, there is not anything resembling universal agreement on the practices that should be followed with respect to withdrawing and withholding treatment.

Zahedi, et al provide three case examples of how Islamic teaching enters into these end of life traditions. In case one, the discussion centers on the right of a patient to refuse chemotherapy treatment for cancer while acknowledging that if this treatment would only prolong the process of dying, Islam would probably allow the alleviation of pain through palliative care. If the patient is a child, Muslim parents are responsible for considering the child’s best interests through consultation with physicians and if they do not could be answerable to courts.566

In the second and third cases presented by Zahedi, et al, it is acknowledged that decisionmaking regarding the withdrawing or withholding of treatment is difficult especially when a patient and/or his family are not in agreement with the medical team’s decision. Islam does hold that resorting to futile treatments to put off death is not acceptable and if there is no reason to anticipate benefits from a treatment, it can be withheld. However, limitations of therapy for adults and children must be positioned within the Islamic recognition that death is an inevitable element of life and that all humans have the right to be treated with respect and without violence.567

Islam advances the ethical rule that “no harm should be inflicted or reciprocated,” a rule which “allows for important distinctions and rules about life sustaining treatments in terminally ill patients; the distinctions on which ethical decisions are made include the difference between killing (active euthanasia) and letting die (passive euthanasia).”568 Islam does not see withholding or withdrawing treatment from a patient identified as brain dead as a form of euthanasia. Thus, in this instance it would be ethical and spiritually permissible to withdraw or
withhold treatment. Some Muslim scholars do take the position that patients or their guardians can refuse treatments that do not improve their condition or quality of life, thus accepting the right of an individual to refuse a death delaying treatment.

As Zahedi, et al have noted, “in this instance, delaying the inevitable death through life sustaining treatment is neither in the patient’s nor the public’s best interests because of limited financial resources. Withdrawal of life sustaining treatments in such instances is seen as allowing death to take its natural course.”569 When a physician and family and patient all agree on the futility of a treatment and perceive it as disproportionate, Muslim jurists often accept the informed refusal of treatment which can be anticipated in the form of a living will or a DNR order.

However, there are still many debates about these and related issues in Islamic societies. Most Muslim jurists, confronted with the necessity of ruling on requests to withdraw treatment, have held that once invasive treatment has been intensified to save or prolong the life of a patient, lifesaving equipment cannot be turned off unless physicians are certain about the inevitability of death. What this means, in essence, is that decisions regarding withholding and withdrawing treatment from any patient are enormously complicated and emotionally charged.570

A study conducted by Masood, Said, Faris, Al Mussady, and Al Jundi on this issue consisted of a retrospective observational research effort centered in the ICU of a tertiary care center in the United Arab Emirates. The UAE is also a Muslim country in which the tenets of Islam apply to questions of withdrawing and withholding treatment. In this study, Masood, et al examined the records of all ICU patients who died for a six month period.571

The research found that while withdrawing and withholding practices were acceptable from an ethical point of view, rarely were life sustaining yet potentially futile treatments
withdrawn in this tertiary care setting. Conversely, withholding was revealed to be the preferred method of limiting end of life interventions. Aggressive interventions such as dialysis and mechanical ventilation were often withheld because of the conviction of physicians that they were futile and would add nothing to the quality of a patient’s life. Instead of offering futile care, the physicians whose patients were considered in this study were offered palliative care that eased their suffering without unnecessarily extending their lives.\textsuperscript{572}

The conundrum confronting many Muslim physicians regarding end of life care are often addressed through fatwas that are issued by Muslim clerics. As reported by Van den Branden and Broeckaert, Muslim fatwas speak firmly against every form of active termination of life.\textsuperscript{573} These pronouncements are based on Quranic verses and prophetic traditions that are widely known and accepted throughout Islam. Their intent is to offer normative Islamic guidance to Muslim doctors in both Muslim and non-Muslim majority countries.

Such documents affirm the centrality of the ethical rule that harm should not be inflicted on others. Such rules go beyond preventing harm and speak to the differences between foregoing treatment and a natural death. It is worth noting that there is no immunity under Islamic law for a physician who unilaterally and actively decides to assist a patient to die. That said, there are two instances in which passive assistance can be provided:

- A physician can administer pain relief that might shorten life but which is given to relieve physical pain and psychological distress rather than to kill.
- A patient may refuse a death delaying treatment or a physician, after consulting with involved parties, may withdraw futile treatment on the basis of informed consent.\textsuperscript{574}
Withdrawing life sustaining treatments in such situations is perceived as allowing death to take its natural course. This may be, to some extent, a fairly fine line between having and not having the intention of causing death. It tends to underscore the complexity of an issue that continues to trouble physicians and patients in Muslim countries like Saudi Arabia where critical care medicine remains somewhat underdeveloped even though there have been substantial advances in the past twenty to thirty years.

A brief discussion of the Saudi healthcare system can help to eliminate this particular challenge. It was not until the middle of the twentieth century that anything resembling an organized healthcare system existed in Saudi Arabia. While the rest of the world in the West was coming to terms with questions of informed consent, euthanasia, and the withdrawing and withholding of care, physicians in Saudi Arabia were working to create a viable national healthcare system that would meet the needs of a burgeoning population that was scattered over a land mass of 2.0 million square kilometers.\textsuperscript{575}

With a population of 25.4 million plus, many of whom live in remote rural areas, the challenge of establishing a comprehensive countrywide healthcare system has been enormous. In 1970, there were only 1,172 physicians and 3,267 nurses in the Kingdom and most of these were not Saudi nationals. Khaliq notes that since that time, the government of Saudi Arabia has invested heavily in educating healthcare professionals, building and staffing primary, secondary, and tertiary care institutions, and enhancing the overall quality of care that is available to Saudi Arabians.\textsuperscript{576}

Integral to the process is the development of norms and systems for addressing the issues that have been examined herein. For Saudis, the transition from an archaic to a modern
healthcare system has had multiple implications and has necessitated many different responses from stakeholders. In the next section of this dissertation, the way forward will be considered.

D. The Way Forward

The Saudi Arabian end of life care system has, as the foregoing discussion demonstrates, made some fairly significant strides forward in terms of treatment practices promoting withdrawal or withholding of treatment in the case of terminally ill patients. However, while this is true, a major concern is that the policies guiding these practices in Saudi Arabia tend to be focused on the physician and not the patient. This is a fundamental distinction between such practices in Western medical settings and those of the Islamic world.577

Some physicians in the United States advance the principle of proportionality as the foundation of such decisions. The principle of proportionality essentially asserts that the use of medical therapies and interventions should be proportional to or assessed with respect to the probability that a positive benefit will be realized. In other words, if a treatment is viewed by physicians as likely to be futile, the principle of proportionality would call for refusing to provide it or withdrawing it once it was implemented.578

Futility can be advanced in any medical setting as a viable reason for withholding or withdrawing treatment. Nevertheless, futility is still seen by many as a controversial, uncertain, and difficult to qualify or quantify concept. It is also possible that differing views on futility are likely to be expressed when one considers the stakeholders in a withdrawing or withholding decision. Not all physicians will agree on this subject and many family members or patients themselves may be extremely reluctant to withdraw or withhold treatment because they lack knowledge of what does and does not comprise futility.579
In Saudi Arabia, where withholding and withdrawing decisions must be made by no fewer than three physicians, two of whom are consultants and one of whom is the primary care provider, assuming agreement is even more unlikely. This was emphasized by Alamri who also pointed out that the lack of palliative care coursework during medical school and residencies is likely to add to the reluctance of many Saudi physicians to recommend withholding or withdrawing treatment.\textsuperscript{580}

One of the key recommendations, therefore, is that Saudi medical schools and residency programs should incorporate more programs and courses that are centered on withdrawing and withholding care and directing the procedures that will be undertaken in order to implement such decisions. Babgi emphasized the importance of providing up and coming physicians with the kind of skills, knowledge, and training that will better prepare them to address these issues.\textsuperscript{581}

Proper understanding of the meaning of futility and the distinctions between active and passive euthanasia can go a long way in making the role of the physician more comfortable in such cases. At the same time that training matters, it is also important for Saudi Arabian medical institutions to develop and promulgate the kinds of policies and guidance protocols that will themselves be beneficial to physicians who must make these decisions. This was an issue that was thoroughly addressed by Al Dorzi, Ajathlany, Aldawood, and Arabi, who pointed out that many physicians who have been in practice for some time in the Kingdom remain fundamentally unsure as to what specific policies on withdrawing and withholding treatment are operative at their institution.\textsuperscript{582}

Additionally, while the literature does suggest that the DNR/No Code and living will protocols are being implemented more and more commonly in Saudi Arabia, it would be useful for physicians and imams in the Kingdom to agree on the proper wording and use of these
instruments. Presented below is a typical example of a detailed living will that can be modified to meet the needs of physicians and patients in Saudi Arabia.

Example of a Living Will

Directions

1. I instruct my attending doctors or primary care givers to withhold or withdraw any life-sustaining medical care or treatment that is only serving to prolong the process of my death should I be in an incurable or irreversible physical or mental condition with no medical expectation of recovery.

2. I instruct that treatment be limited to methods which are designed to keep me in comfort and free of pain, including any pain which might result from withholding or withdrawing any life sustaining medical treatment.

3. I instruct that if I am in any of the conditions described in item 1, that it be remembered that I specifically DO NOT want the following types of medical care or treatment:
   A. ____________________________
   B. ____________________________
   C. ____________________________
   D. ____________________________
   E. ____________________________
   F. ____________________________
   G. ____________________________
   H. ____________________________

4. I instruct that if I am in any of the conditions described in item 1, that it be remembered that I specifically DO want the following types of medical care or treatment:
   A. ____________________________
   B. ____________________________
   C. ____________________________
   D. ____________________________
   E. ____________________________
   F. ____________________________
   G. ____________________________
H. __________________________

5. I instruct that if I am in the condition described in item 1, and if I have the affliction or afflictions of the following disease, illness or injury, that I receive the following medical treatment and care:

This Living Will Declaration is made the _________ day of _________, 20__________.

______________________________________________________ Signature

Witness Statements

I declare that the persons who have signed this document are personally known to me, that the undersigned have acknowledged this Living Will Declaration in my presence, and that the undersigned are of sound mind and are under no duress, fraud or other influence.

___________________________________ Date___________________ Witness

Signature

___________________________________ Date___________________ Witness

583Signature

This living will could be augmented by including signatures of a primary care physician and any consulting physicians. It would certainly serve to signal to caregivers that the patient has given some thought to the question of how he or she wishes to approach the end of life and what steps are and are not acceptable as death approaches. Of course, the living will requires some fundamental understanding of one’s condition and the treatment options that are available along with their positive and negative consequences.

In this context, it is reasonable to argue that one of the responses of physicians to such issues should be developing more effective mechanisms for patient education. Critical care medicine is rapidly being developed in Saudi Arabia due to ongoing government investment in healthcare systems. Educating new generations of physicians, nurses, and technicians is a part of this process but it is a process that must also incorporate the education of the Saudi public. 584
Given that religion is said to be the most important factor shaping Saudi culture, any educational efforts that are centered on these complex questions must necessarily include members of the Islamic clergy. This chapter has demonstrated that the clerics of Saudi Arabia are responding to questions of withholding and withdrawing treatment, of futility, and of issues that are related to patient autonomy.\textsuperscript{585} Certainly, the way forward requires recognition that modern medical practices are not necessarily incompatible with the fundamental tenets of Islam or with the physicians’ mandate to do no harm and to always respect human life and its sanctity.

Perhaps acknowledging that withdrawing or withholding care (or both) are integral to palliative care treatment should be included in the educational process and in developing normative guidelines. Muslims do believe in the inevitability of death and in the principle that it is only Allah who determines when an individual dies.\textsuperscript{586} Physicians may function in end of life situations as actors who can assist the dying patient come to terms with the will of Allah. While Islam does value suffering, pain, endurance, and patience, this does not mean that it is correct or caring to stigmatize those patients who accept treatment withdrawal as a precursor to ending suffering or those patients who choose opioid or other pain relief treatments as death approaches as doing something wrong or immoral.

Finally, it is important to engage jurists in the Saudi legal system of Sharia’h who often come into this particular decisionmaking process.\textsuperscript{587} These jurists, who are also clerics, exercise enormous influence over all aspects of Saudi culture. They are particularly influential in terms of medical decisionmaking. The advances of medical sciences are such that it is incumbent upon all of the actors in the Saudi medical system to acknowledge the reality of these advances and to develop responses to them.
The way forward does not necessitate transporting the United States healthcare system and its cultural norms and practices to Saudi Arabia. It is quite possible for Saudi stakeholders to take from the United States and other Western countries those practices that are likely to fit best with Islamic beliefs and Saudi cultural traditions. This would require willingness on the part of many different individuals and groups to learn from other cultures.

It is particularly important to consider enhanced involvement of patients and their families in the decisionmaking process at the end of life. Educational campaigns targeting Saudi healthcare consumers, medical professionals, clerics, jurists, and members of the government such as those in the Ministry of Health are desirable. Bringing about meaningful change and understanding the demands of autonomy that are a part of one’s respect for the dignity of the human being are desirable activities.

Conclusions

Withdrawing and withholding futile treatment is admittedly a challenging subject in any culture, but particularly challenging in the context of a culture in which authoritarianism shapes physician-patient and society-individual relationships. There are no hard and fast guidelines available even in the United States as to the differences between ordinary and extraordinary interventions. As the legal cases discussed above indicate, achieving consensus on the futility of hydration and nutrition has proven to be difficult at best. If this is the case in the United States, it is an even more complex issue in Saudi Arabia.

This chapter leads to the conclusion that the Saudi Arabian healthcare system can be enhanced by adopting some of the elements found in the American healthcare system that deal with withdrawing and withholding treatment at the end of life. Moving forward, it will be interesting to see how these issues are addressed and how different groups within the Kingdom
will respond to these concerns. There is certainly room for improvement in the Saudi system. Determining how desirable improvements will be undertaken seems to be a necessity.

This chapter has presented several recommendations for modifying the existing Saudi system. The final chapter of this study will present a detailed discussion of these recommendations in light of the various medical, cultural, social, and religious issues that have been introduced herein. These recommendations will be both practical and theoretical and will reflect an enhanced understanding of what has become endemic in Saudi culture: an instinctive resistance to certain kinds of change particularly when those changes represent the adoption of ideas originating in non-Muslim societies.
Chapter Seven

Summary, Conclusions and Recommendations

Introduction to the Chapter

This discussion of the similarities and differences that can be observed when one compares end of life care as delivered within the United States healthcare system to practices of this type in the Kingdom of Saudi Arabia has given a great deal of attention to a number of critical variables that have shaped the different systems in which healthcare services for the terminally ill are delivered. Incorporated in this discussion are such items as a review of American and Saudi Arabian end of life care practices (contained in Chapters Two and Three), a comparison between intensive care systems and palliative care systems in the two countries (Chapters Four and Five), and the withdrawing or withholding practices in the two countries (Chapter Six).

This final chapter of the study offers a summary of what has been learned, conclusions regarding its significance, an assessment of “the way forward” for Saudi Arabia as it continues what Alaiyan and Al-Hazzani have called the modernization and the attendant improvement of end of life palliative care in Saudi Arabia.589 The chapter also presents targeted recommendations centered first on the needed practices for improving the Saudi system and secondly, for additional research on the system as it now exists, attitudes of Saudi healthcare professionals regarding the system and possible changes to it, and other critical research tasks.

According to Babbie, qualitative research of the kind represented by this dissertation project is essentially exploratory in nature.590 Qualitative research is highly valuable and serves often as a springboard to quantitative or empirical studies. It tends to provide a rationale or
justification for considering explanatory research that adds to our understanding of a particular phenomenon or event. This of course, speaks to the limitations that are implicit in the present study – limitations identified in Chapter One, Introduction.

Summary of the Study

If anything, this study serves to illustrate the fact that the literature on end of life care is global in its scope, both broad and deep, and nevertheless inconclusive in some particulars. It is clear that trends in the global healthcare system are continually evolving; what is considered to be state of the art knowledge, treatment, or interventions yesterday may be replaced tomorrow as new research, new technologies, and paradigms emerge, are tested, and then incorporated into a healthcare delivery system. This statement is as relevant with respect to end of life care as it is to any other aspect of medical service delivery.591

Bullock says that end of life care systems incorporate a number of interventions that not only target the terminally ill patient but also their families and significant others.592 End of life care is delivered not only to the dying patient. It is also designed to offer comfort and help to the family and loved ones of the patient and to assist them in coming to terms with the loss of a loved one. It can include spiritual or psychological counseling as well as medical treatments and interventions. It can and should foster effective utilization of healthcare resources while ideally reducing some of the costs of delivering services in those cases where cost is of concern.

The research demonstrates that in both the United States and in Saudi Arabia, the overarching goal of the healthcare delivery system is to advance a curative mentality. This mentality derives in some measure from recognition of the necessity of eliminating and responding to infectious diseases. As more and more vaccines have been developed targeting such diseases as smallpox, measles, chicken pox, hepatitis, and pneumonia, there has been
something of a shift in the focus of research in the medical field. This shift has resulted in an emphasis on caring for and treating a growing number of patients from around the world who must cope with chronic medical conditions such as diabetes, cardiovascular disease, and even cancers.

Many of these conditions, along with trauma and genetic predispositions or birth defects, are associated with high levels of morbidity and mortality. Confronted with the reality of a terminal illness that is unresponsive to curative treatment, medical professionals have turned their attention to the development of the kinds of end of life interventions that can contribute to the physical, psychological, and spiritual well-being of the patient. The development of palliative care treatments, which has been pioneered in the United States and other Western countries, is evidence of this particular paradigm shift.

From palliative care to the creation of hospices, end of life care has emerged as a standalone subspecialty or discipline within the medical field. As defined by Fowler and Hammer, each of these approaches to end of life care are understood as providing viable and helpful care to a patient who is terminally ill and for whom no other interventions are available that could sustain life, cure an illness, or restore a failing organ.

Added to palliative care and intensive care interventions are the practices of withholding or withdrawing treatment. Many medical professionals in both the United States and Saudi Arabia have significant ethical concerns regarding questions of withdrawing and withholding care. These concerns include but are not limited to considerations regarding religious beliefs. As this study has revealed, religion is a key determinant of the ethical orientation of healthcare practice in the global community. The research demonstrates that in Saudi Arabia, which has been accurately described herein as a highly traditional and conservative Muslim country,
withdrawing and withholding treatment are often viewed with mistrust as an effort to usurp the role of God in determining the span of an individual’s life.\textsuperscript{597}

The research also suggests that bioethical challenges impact upon all aspects of end of life care. Zahedi, Larijani, and Bazzaz put it this way: “advances in modern technology have blurred many of the lines and distinctions that once seemed so clear; including life and death. Currently, end of life issues are one of the top 10 healthcare ethics challenges facing the public.”\textsuperscript{598} One of the critical differences that this study identifies between the American healthcare system and that of Saudi Arabia is that in the United States, it is expected and even required that patients and/or their guardians or significant others participate actively in making end of life decisions. This is not the case in Saudi Arabia where doctors are seen as possessing higher levels of authority than laypeople and where family members often place their trust in the capacity of physicians to make decisions that are in the best interests of the terminally ill patient.\textsuperscript{599}

For example, the doctrine of informed consent is a fundamental tenet of the U.S. healthcare system but it is not as deeply enshrined at the present time in the Saudi Arabian system.\textsuperscript{600} Informed consent is a doctrine as well as a process. It is predicated upon the belief that the individual has a fundamental right to autonomy. It assumes the existence of agency or the capacity of the individual to process medical information (i.e., to be informed) and to make a personal decision about their own situation (i.e., providing consent to either treatment or the lack thereof). In Western cultures, informed consent is a vital element in medical ethics.

Islamic views on informed consent are positioned within the belief that God must be trusted, that God is in charge of man’s destiny, and that God is possessed of divine sagacity.\textsuperscript{601} In theory if not necessarily in universal reality, the Muslim’s trust in God is seen as putting an end
to fear of such ills as poverty, helplessness, and devastation; it is even supposed to put an end to the fear of death and to ensure that the terminally ill Muslim will be comfortable in placing his or her fate in the hands of God rather than a physician. Informed consent, therefore, is understood differently in the United States and Saudi Arabia as well as other Muslim majority countries.

There are also significant differences to be observed when one compares the issue of palliative care. Opioid use as part of the treatment of end stage diseases is accepted in Western countries as a standard component of such care.\textsuperscript{602} Again, there are debates still underway in Muslim countries, including Saudi Arabia, as to the administration of opioids and other types of palliative care treatments. The research suggests that many physicians in the Kingdom are themselves not fully cognizant of when and where such treatment should be offered or withheld.\textsuperscript{603}

Islamic bioethics respond to sacred law and not the natural law or any particular rights-based legal system.\textsuperscript{604} This statement applies to the present discussion with respect not only to the use of opioids but also:

- Passive and active euthanasia.
- Physician assisted suicide.
- Withdrawing/withholding of treatment.
- Decisionmaking responsibility for end of life care.

Again, one must make note of the fact that the Saudi medical system is firmly positioned with Islamic bioethics and as a consequence is less focused on any perception of whether a particular treatment is or is not futile than on the question of whether or not Islam itself permits certain decisions to be made.
Withdrawing and withholding of treatment appear to be far more controversial in Saudi Arabian medical settings than they are in the United States. The question of the appropriateness of either of these end of life practices is certainly linked to the Muslim understanding of the inevitability of death and the belief that determining when death occurs is to be left to God and not to human agency. Here again, one finds differences between Saudi Arabia and the United States where family members and the patient are likely to be the primary decisionmakers with respect to determining whether treatments should be stopped if they have been initiated or withheld. Saudi physicians seem to be more likely to inform families that treatment is going to be withdrawn or withheld than to engage families in making this critical decision – in those cases where either practice is actually implemented.

Futility of treatment is an important issue identified in the literature focused on both Saudi Arabia and the United States. The research reveals that the issue is seen as somewhat more pressing in the United States than it is in Saudi Arabia where discussions of futility are likely to be contextualized with respect to Islamic ethics and jurisprudence. Futility of care in the United States may speak more directly to issues of resource allocation and cost reduction than is likely in Saudi Arabia.

Questions of the futility of treatment were addressed at some length herein. Again, futility is understood differently in the two countries. On balance, it would appear that practitioners in the United States are more focused on assessments of the futility of treatment than are health practitioners in the Kingdom where treatment for the terminally ill are likely to be maintained for longer periods of time than they are in the United States. One might want to point out that futility of treatment is related in some ways to issue of cost containment which are significant in the United States to a somewhat greater extent than they may be in Saudi Arabia.
Regardless of the country, Bagbi has stated that end of life care systems are all oriented toward improving the quality of life that is experienced by patients.\textsuperscript{608} The proliferation of ICUs in the Kingdom is of relatively recent origin and it is this movement toward the modernization and improvement of the Saudi healthcare system that the research suggests can be linked to the topics discussed herein. One of the differences observed when the two countries are compared is that it is the ICU and not the hospice where the terminally ill Saudi patient is likely to receive any care as death approaches.

The study does tend to highlight the fact that end of life care practices, protocols, and guidelines are more advanced and established in the United States and other Western countries than they are in Saudi Arabia and other majority Muslim nations.\textsuperscript{609} Both physician assisted suicide and passive euthanasia are accepted in certain jurisdictions in the United States where the concept of “death with dignity” has gained some traction. These are important ethical issues which are not being debated widely in the Kingdom because of culture as well as religion. That said, it is important to note that both in the United States and in Saudi Arabia, the primary obligation of the physician is understood as providing care and alleviating pain and sparing individuals unnecessary suffering. It is the type of action oriented toward these outcomes that differs rather than the primary role of the physician.

Another difference observed herein centers on the use of “do not resuscitate” (DNR) orders and those legal documents know as either Advanced Directives or Living Wills. Research by Sonfield centers on concerns regarding the perceived rights of patients in the United States to make decisions regarding end of life care or the possible outcomes of other medical conditions.\textsuperscript{610} Both living wills and DNRs are much more likely to be executed in the United States than in Saudi Arabia. This is not to say that these tools for providing patients with the
ability to determine how they will and will not accept healthcare interventions are not in use in Saudi Arabia. Suffice it to say that for the most part, these instruments are still relatively new and poorly understood in medical care settings in the Kingdom even when doctors themselves have been trained in the United States or other Western countries.

It is worth pointing out as does Ur-Rahman, Arabi, Adhami, Parker, and Al-Shimemeri that the availability of advanced medical care and life support has given rise to complex issues in the Kingdom and to corresponding moral, ethical, and legal dilemmas. The right to die is not well accepted or defined in most countries but it is particularly not defined through formal standards and regulations concerning DNR orders in Saudi Arabia. Efforts to understand how physicians in the Kingdom respond to these concerns have been ongoing but it is still somewhat unclear as to how the Saudi Arabian medical system is responding to such issues.

The study does suggest that there are changes taking place across the Kingdom in regard to these issues. Tokrouri and Halwani reported that more and more Saudi educational institutions charged with physician training are incorporating education on DNRs, living wills, informed consent, and withdrawing and withholding treatment. These changes are gradual as one would undoubtedly anticipate particularly in light of the fact that the Kingdom is as has frequently been noted herein, a very conservative society and one in which traditional culture and religion (which are integral in terms of their impact upon all aspects of national life) are not known for accepting change readily.

Conclusions

i. Conclusions Regarding the Research Method
The purpose of this dissertation research project was to construct a comparative analysis of the ways in which the United States and the Saudi Arabian medical systems address end of life care. The analysis was focused on identifying similarities and differences that can be observed when the two countries are compared and identifying the causal explanations for those similarities and differences. The method employed in the pursuit of this goal was that of a qualitative case study in which comparisons of the two countries formed the method and the medical care systems in the countries formed the case. This is an example of what is known as the Small N case study approach.

According to Dooley, such research is “an inquiry investigating a contemporary phenomenon within its real-life context, when the boundaries between phenomenon and context are not clearly evident; and in which multiple sources of evidence are used.”613 This methodology employs a small sample of cases rather than a single case or a larger number of cases. Driven as noted above neither by generalization or prediction, the method is designed to emphasize a specific interest or issue and to gain understanding of it by observing each of the variables that are relevant as well as their interacting relationships.

This method is viewed widely as appropriate in the social sciences and in those research instances in which a central goal is to analyze and gain heightened insight into perplexing social issues that emerge in a climate where volatility can be observed.614 One of the acknowledged challenges of the Small N comparative case study is that it tends to reveal that many key variables are overlapping with one another.

One of the conclusions that can be drawn as a consequence of this study is that this particular criticism is quite valid. For example, much of the discussion contained in Chapters Two through Six is derived from what amounts to a comparatively small sample of scholarly
studies in which questions regarding end of life care in general, palliative care, hospices, DNRs and Living Wills, the futility of treatment and withdrawing/withholding treatment are jointly discussed. This is not to suggest that these individual issues are identical; palliative care and hospice care are clearly not one and the same thing although the literature indicates that palliative care is often a key feature in the hospice setting.615

Thus, the Small N comparative case study as demonstrated herein emerges as a useful tool for the exploratory stages of a research topic.616 The goal herein was exploration leading to the development of a set of somewhat narrowly focused conclusions regarding similarities and differences between the United States and Saudi Arabia. In the process of exploring the issues, some explanation was also forthcoming as to why these differences exist. The study does serve to illustrate the importance as well as the usefulness of this kind of research as it is relevant to the medical field and a specific aspect of that field. While Small N case studies are generally found in other academic disciplines and are not as common in healthcare as they are, for example, in political science or history, this study does serve to demonstrate that the methodology is sufficiently flexible to be employed in the healthcare field.

ii. **Key Variables Appearing to Impact Upon the U.S. and Saudi Healthcare Systems**

Inevitably, there are a number of variables that directly impact upon the ways in which a country structures, delivers, and evaluates its response to the healthcare needs of its citizenry. Money matters, technology is significant, infrastructure plays a role, and the availability of personnel is also of significance. While each of these variables are quite important in determining how end of life care will be delivered and even conceptualized in a particular country, this research suggests that before such variables can be taken into consideration, one must look at questions related to culture itself.617
Discussions of culture also introduce discussions of the role that is played by religion and jurisprudence in shaping medical practice. The literature herein reveals that to a much greater extent in Saudi Arabia than is the case in the United States and other Western countries, religion is a key factor shaping each and every manifestation of culture.\textsuperscript{618} No one would disagree with the conclusion that while Saudi Arabia is not a theocracy in the same sense that Iran is a theocracy governed primarily by members of the clergy, it is unlikely that there will be any meaningful disagreement on the conclusion that Islam plays a much greater role in providing the ethical as well as the practical foundations for end of life care in Saudi Arabia than any religion (including Christianity) is likely to play in a more diverse country such as the United States.

Islamic jurisprudence is the norm in the Kingdom when it comes to determining what kinds of behaviors are and are not acceptable and what kinds of healthcare policies must be respected and adopted.\textsuperscript{619} Both Shari’a law and civil law in the Kingdom reflect the fundamental tenets of Islam as revealed to the Prophet Mohammad and enshrined in the Qur’an and further explicated in both the Hadiths and more contemporaneous fatwas. Muslim physicians perceive themselves as bound by these regulatory systems in ways that their Western and American counterparts are likely to perceive themselves as bound in their practice by the standards of their profession and the civil law of their country.

The result of this sense of necessary adherence in the Kingdom to each and every one of the principles of Islam cannot be overstated.\textsuperscript{620} The ethical constructs that are normative in Saudi Arabia’s healthcare system are derived exclusively from Islam. While certainly Judeo-Christian ethics are extremely important in shaping biomedical ethical practice in the United States, it is highly unlikely that a typical American physician would seek approval from a
member of the clergy before considering withdrawing or withholding treatment from a patient. Such behaviors are hardly unknown among Saudi physicians.

In point of fact, the research discussed herein indicates that religion is the most important factor in Saudi Arabian culture. Islam as has been described herein is of the belief that there is a role in life to be played by the experiences of pain and suffering and that, more significantly, the life of the individual is totally in the hands of God. This results at times in what seems to be a reluctance for using extensive opioids to reduce pain experienced by the terminally ill patient whereas opioid use is a cornerstone of both palliative and hospice care in the United States.

Only gradually are medical care providers in the Kingdom – both institutions and physicians themselves – becoming comfortable with extensive use of opioids and other aspects of palliative care such as withdrawing or withholding treatments that may be futile. While the ICU is becoming a more and more widely available treatment locus in Saudi Arabia, the same cannot be said for hospices. Just as Saudi physicians are often reluctant to suggest to their patients or others that care should be withheld or withdrawn, so are many Saudi healthcare consumers unwilling to make these kinds of decisions.

In discussing the role of culture in shaping medical care delivery systems, one must also consider questions of how a culture allocates authority. Saudi Arabia is essentially a patriarchal culture and one in which individuals of high status including doctors are viewed as authorities upon whom one can and must rely when it comes to making important decisions. The Saudi physician occupies and may be said to enjoy a degree of authority vis-à-vis decisionmaking that the physician in the United States does not possess. This is not to suggest that American physicians are lacking in other professional status or the authority that comes from expertise.
At the same time, it is clear that the culture of the United States is one in which the rights of the individual are given a primacy that is not to be found in Saudi Arabia. The pioneering efforts which have established such instruments as DNRs, Living Wills, and advanced directives emerged in the United States and other Western countries. The doctrine of informed consent that has over time become a key determinant of patient participation in medical decisionmaking is also uniquely Western and is predicated upon the conviction that regardless of lay status, the patient has an inherent right to make decisions regarding his or her care based upon comprehensive information about their condition, the interventions or treatments offered, and the possible outcomes of those treatments.

One cannot stress enough the cultural differences between the U.S. and Saudi Arabia and the role that these differences play in shaping aspects of end of life medical care. These cultural differences directly impact upon societal perceptions of the role of the physician, the rights of the individual, and the nature of the relationships between the physician and the patient and his or her family members. Such differences also are reflected in – or in the case of Saudi Arabia, determined by – the interaction between religion and its tenets and ethical norms and social norms and mores. In Saudi Arabia, as noted several times herein, Islamic jurisprudence shapes and informs most aspects of medical practice. Hospitals, for example, have members of the clergy on their ethics committees and directorial boards; this is not the case in the United States, except when a medical institution is owned and operated by a faith-based organization.

**iii. Normative and Ethical Comparison of the Two Systems**

The study did not generate any new statistical data, but does permit narrative comparison of the target cases. Based on the analysis conducted in this dissertation project, one can make some broad comparisons between the normative principles and ethical underpinnings of the two
national medical systems. Drawing upon the literature cited throughout the study, the following side-by-side comparison table was developed by the researcher to highlight these differences.

Comparison of Ethical Norms: U.S. and Saudi Arabia

<table>
<thead>
<tr>
<th>Ethical Norm/Construct</th>
<th>US</th>
<th>Saudi Arabia</th>
</tr>
</thead>
<tbody>
<tr>
<td>Patient Autonomy</td>
<td>Key Concern</td>
<td>Secondary Concern</td>
</tr>
<tr>
<td>Right to Self-Determination</td>
<td>Preserved</td>
<td>Limited</td>
</tr>
<tr>
<td>Justice</td>
<td>Key Concern</td>
<td>Key Concern</td>
</tr>
<tr>
<td>Compassion/Beneficence</td>
<td>Key Concern</td>
<td>Key Concern</td>
</tr>
<tr>
<td>Proportionality</td>
<td>Key Concern</td>
<td>Key Concern</td>
</tr>
<tr>
<td>Sanctity of Life</td>
<td>Secondary Concern</td>
<td>Key Concern</td>
</tr>
<tr>
<td>Death with Dignity</td>
<td>Concern</td>
<td>Less Significant</td>
</tr>
<tr>
<td>Patient Involvement</td>
<td>Key Concern</td>
<td>Secondary Concern</td>
</tr>
<tr>
<td>Communication</td>
<td>Essential</td>
<td>Limited</td>
</tr>
<tr>
<td>Resource Allocation</td>
<td>Key Concern</td>
<td>Secondary Concern</td>
</tr>
<tr>
<td>Cost Savings</td>
<td>Key Concern</td>
<td>Limited Concern</td>
</tr>
</tbody>
</table>

This summary reflects the fact that the literature identifies patient autonomy as represented by issues of Informed Consent, DNRs, advanced directives, and so on as much more fundamental a concern in the United States than in Saudi Arabia. The ethical issues confronting doctors in both countries are, however, similar, particularly when it comes to quality of end of life care, withdrawing and withholding and withdrawing treatment, determination of
treatment futility, and the proper role of medical caregivers in such practices as euthanasia or physician assisted suicide.

It is quite clear that culture as described above has shaped and informed both medical systems. Obligations rather than rights are central to Saudi society which is essentially a collectivist society in which authority tends to be vested in professionals and people in positions of power rather than in the individual. The Islamic tradition is deeply entrenched within Saudi culture. While one can argue that the Judeo-Christian tradition is equally integral to Western society, the separation of Church and State that has come to typify the relationship between relation and society in the United States simply does not exist in Saudi Arabia.

On the one hand, this may be seen as contributing to a degree of societal stability and homogeneity that to some extent simplifies the delivery of end of life care in the Kingdom. When physicians are not compelled to be fully open in communicating with patients or their families and are empowered to make critical decisions regarding DNRs, and withholding or withdrawing treatment, the responsibility shifts from the individual to the institution. This denies a patient and his or her family the right to fully understand the situation they confront and to at least share in determining what kinds of care will be accepted or rejected.

At the same time that these concerns are being expressed by many medical practitioners in Saudi Arabia, there are signs that changes are underway in the Kingdom that speak to these issues. The literature reveals that more medical institutions in Saudi Arabia are establishing ICUs, palliative care programs, and rudimentary hospices. These are steps forward that are being developed in tandem with enhanced training of Saudi medical students with respect to end of life treatment options. New technologies and new interventions that are becoming more readily available in Saudi Arabia may be seen as driving these transitions and as encouraging the
development of more proactive policies and protocols that are centered on engaging patients and their families in making decisions about end of life care.

Research indicates that palliative sedation is regarded as indispensable in managing unbearable suffering experienced by the terminally ill patient. The problem is significant because many nurses and physicians remain vehemently opposed to any form of physician assisted suicide while others question the fundamental difference between palliative sedation and euthanasia. Healthcare professionals are often uncertain as to whether or not palliative sedation is appropriate in light of the possibility of other therapeutic interventions, the appropriate role of healthcare providers, and the biomedical rigor of diagnosis. The problem is also significant in light of the fact that professional healthcare providers are admonished to do no harm and to apply ethical standards to every action and choice.

As noted above, the problem examined herein speaks to the identification of ethical dilemmas and barriers that caregivers confront in using palliative sedation at the end of a patient’s life. It focuses on the extent to which caregivers perceive themselves as competent to diagnose a patient as terminal and to recommend or offer palliative sedation when other therapeutic interventions have proven futile. The problem is common in caring for patients with end stage cancer and other illnesses.

Ethically, various researchers have attempted to identify a foundation that can be employed by caregivers with respect to offering palliative sedation. Many healthcare providers are unsure as to how palliative sedation for intractable end of life distress is actually differentiated from physician assisted suicide or euthanasia.

The research question presented herein speaks to an ethical dilemma that many healthcare providers in both the U.S. and Saudi Arabia must face: when palliative sedation leading to
terminal somnolence should be offered or given to the terminally ill patient. There is no doubt that continuous deep palliative sedation at the end of life introduces significant ethical concerns for many. There are concerns expressed by some physicians that there are no substantive differences between physician aid in dying and palliative sedation.

Of course, palliative sedation reduces refractory suffering and the need for assisted death through psychosocial and spiritual support as well as aggressive symptom management. However, aggressive palliative sedation may lead to prolongation of life lacking any element associated with quality of life such as sentience, cognitive function, or even dignity. The ethical issue engages one with questions of patient autonomy. Palliative sedation may remove the ability of a patient to change a decision once treatment has begun, leading many caregivers to consider it to be significantly like physician assisted suicide.

iv. Recommendations for Change

Based upon the foregoing discussion, a number of recommendations for improving Saudi end of life care can be offered with the objective of mounting a more patient centered response to the very real stresses and fears that even the faithful Muslim must experience as the end of life nears. While it is true that Muslims see themselves as in the hands of God and believe that God will end their lives when it is fitting and appropriate, and while it is believed that such principals of faith will eliminate the fear of death, the reality is that most people in most countries and cultures do fear dying.629

The first recommendation in this general category is adopting a patient centered approach to end of life decisionmaking and moving away from the current physician centered ethos that prevails. Saudi physicians, like their Western counterparts, are already committed as they ought to be to principles of compassion, beneficence, non-maleficence, and justice. Unlike their
Western counterparts, Saudi doctors appear to be less driven by concerns regarding resource allocation and cost reductions.\textsuperscript{630} 

While this is a positive aspect of the Saudi healthcare system at the present time, this system nevertheless would benefit from enhancement of patient engagement which could be facilitated by:

- Promotion of more open, honest, and comprehensive communication between physicians, patients, and family members.
- Development of national policies and guidelines on the use of advanced directives, DNRs, and Living Wills as mechanisms for ensuring that patient wishes are understood and honored.
- Improvement of the overall approach to palliative care as a means of alleviating patient suffering during the terminal stages of a condition and enhancing the availability of effective opioids for pain management.
- General education of Saudi healthcare consumers regarding these issues as well as questions about the futility of care and the viability of withholding or withdrawing treatment.
- Improved education of Saudi healthcare system students and practitioners regarding end of life care and establishing awareness among professionals of the interventions that are available to them.

These steps emerge as critical elements in a comprehensive effort to enhance Saudi Arabian end of life care. A three-pronged strategy may need to be implemented in order to bring about desirable changes. The first prong of the strategy focuses on the development of more comprehensive guidelines on what should be incorporated into standards of care for patients at
the end of life. This will necessitate the involvement not only of physicians and managers or directors of medical institutions. The Saudi Ministry of Health will need to play a major role in promulgating such guidelines. Members of the clergy will also need to participate in order to assure that new guidelines are acceptable within the context of Islamic jurisprudence and the faith itself.631

   Inevitably, such an effort will require an examination of controversial ethical issues including voluntary euthanasia, assisted suicide, futility of treatment, and circumstances in which withdrawing or withholding treatment are appropriate.632 One should not underestimate the difficult of meeting this particular challenge. Change is slow in highly traditional and conservative countries such as Saudi Arabia. Many of these issues speak directly to fundamental principles of Islam itself.

   The second prong of the strategy recommended herein focuses on educating physicians in order to make them more sensitive to and responsive to new guidelines.633 This education must begin in medical school and continue through the professional education of established physicians and other healthcare professionals. It is likely that there will be some resistance to guidelines which result in the transfer of some decisionmaking authority from doctors to patients and/or family members. By enhancing the educational role of physicians with respect to these issues, this reluctance may be somewhat offset.

   The third prong of the recommended strategy centers on educating members of the public. One of the cornerstones of the American system is the promotion of healthcare consumer knowledge, health behaviors, and clinical practice itself.634 Western bioethical principles (e.g., autonomy, participation in decisionmaking, and death with dignity) can be adopted in Saudi Arabia only if patients themselves and the general public are made aware of such principles.
One should point out that as more and more Saudi nationals study, live, and work in Western countries, their openness to such attitudes itself is likely to have been enhanced.

These, then, are the specific recommendations for change that have been identified as a consequence of this qualitative study. It must be acknowledged that each of these changes will be difficult to implement. The culture of Saudi Arabia is a barrier to such changes which do speak directly to the question of individual rights as opposed to collective obligations. Nevertheless, medical professionals from across the world have become sensitized to the importance of providing the terminally ill or traumatized patient with palliative care and options for making informed decisions regarding the end of life. Saudi Arabia must embrace the ethical posture which supports patient autonomy and which leads to a devolution of authority from the physician to the patient – a task that is clearly in the best interests of the individual and which also speaks to the importance of exhibiting compassion and practicing medicine within the context of justice.

v. Recommendations for Further Research

The present study sought to combine explanation with exploration in the context of what can best be understood as a Small N comparative case study. While studies of this type are, as discussed herein, methodologically sound and viable, they often introduce questions that they cannot ultimately resolve. This is very much the case in this study, which leads to a set of recommendations as to what type of research could and should be undertaken to further enhance understanding of the issues that have been raised in this dissertation.

First, it is suggested that additional qualitative research involving interpretive phenomenological analysis (IPA) via interviews of Saudi physicians, clerics, Ministry of Health personnel, and healthcare consumers be undertaken. IPA provides a unique opportunity to
identify and assess the lived experiences of individuals impacted by a particular phenomenon.\textsuperscript{635} The actors whose opinions and experiences matter within the Saudi system have a great deal to contribute to this discussion. Securing their input through sets of semi-structured interviews would be enormously informative.

Secondly, survey research is always desirable when one is attempting to gain insight into attitudes, practices, and behaviors.\textsuperscript{636} The aforementioned groups of Saudi healthcare stakeholders can and should be surveyed to assess these attitudes, practices, and behaviors. Qualitative interviews of a limited sample in each group of stakeholders would be a natural springboard for more extensive surveys.

Survey research would be instrumental in identifying the kinds of constraints and challenges which could very well have a negative impact on implementing the recommendations presented above. Survey research is also a cost-effective mechanism for increasing understanding of a phenomenon by expanding the number of individuals whose opinions and views are solicited. It can serve to facilitate comparison of unique stakeholder groups. This in turn can assist policy and decisionmakers in identifying what they need to do in order to bring about meaningful change.

\textit{iv. Limitations of the Study}

The study described herein is limited by a number of factors. The literature on palliative care, end of life care, and relevant matters that are specific to Saudi Arabia is itself limited. Many of the practices discussed herein are relatively new to Saudi Arabia where the healthcare system itself is continuing to evolve and modernize. Additionally, empirical research on the topics discussed in this dissertation is somewhat limited. While limiting, these issues do not in
any way negate the significance of the topic or cast doubt on the conclusions that have been reached by the research.

Qualitative research is always limited to some extent by its reliance upon previously published studies as is the case herein. No new input from stakeholders was obtained in this research effort. Because this is the case, one must be cautious in making any sweeping generalizations regarding the research findings.

Nevertheless, this study should prove interesting and useful to Saudi Arabian healthcare professionals. These individuals have a vested interest in identifying strategies for improving their capacity to enhance patient care and thereby address quality of life issues. Such issues are as significant for the terminally or dying individual as they are for other patients. Given the ethical orientation of Saudi medical practitioners, this study serves to affirm the reasons why compassion, justice, and faith all combine to provide the normative framework for the delivery of medical care to vulnerable and needy patients. Further research as recommended herein would be beneficial going forward.

1 Thomas, K & Lobo, B., (2010). Advance Care Planning in End of Life Care. USA, Oxford University Press. 190
2 Thomas, K & Lobo, B., (2010). Advance Care Planning in End of Life Care. USA, Oxford University Press. 28
7 Silbermann, et al, Ibid., p. 16.
8 Ibid., pp. 16-17.


Hester, op. cit., pp. 34 – 35.

Hester, op. cit., p. 35.


Lieberson, op. cit., p. 318.


Lange, op. cit., p. 4.

Dooley, op. cit., pp. 60-61.


American Cancer Society, op. cit., p. 2.


The End of Life Taskforce (2000). *Faithful Living, Faithful Dying: Anglican Reflections on End of Life Care*. USA, Church Publishing Inc


Beauchamp, T., & Childress, J., (2013). *Principles of Biomedical Ethics*. USA; Oxford University Press. 182- 183


90 Dees, M., Vermooij-Dassen, M., Dekkers, W., & Van Weel, C., (2010). Unbearable suffering of patients with a request for euthanasia or physician-assisted suicide; an integrative review. *Psycho-Oncology.* 19 (1), 339- 352


100 Kelly, D. (2006). *Medical Care at the End of Life; A Catholic Perspective.* USA. Georgetown University Press. 34- 68


112 Kitchen, Ibid., p. 2.


114 Kitchen, op. cit., p. 3.

115 Kitchen, Ibid., p. 3.

116 Kitchen, Ibid., p. 4.


118 Leo, R. (1999). Competency and the Capacity to make Treatment Decision; A Primer for Primary Care Physicians. *Journal of Clinical Psychiatry*. 1 (5): 131- 141


Center for the Study of Health, Faith, and Ethics, 2005), 1.

123 Waugh, 2.

124 Waugh, 2.

125 Waugh, 3.

126 Waugh, passim. 4 – 5.


128 Sachedina, 775.


130 Zahedi, Larijani, and Bazzaz, 11.

131 Zahedi, Larijani, and Bazzaz, 11.

132 Zahedi, Larijani, and Bazzaz, 12.


134 Atighetchi, 32

135 Atighetchi, 32.

136 Atighetchi, 14.


138 Waugh, 16.

139 Sachedina, 775.

140 Sachedina, 776-777.

141 Sachedina, 776.


143 Atighetchi, 40-41.

144 Waugh, 16.

145 Waugh, 3.

146 Waugh, 3.
147 Waugh, 2.


149 Takrouri and Halwani, 187.

150 Takrouri and Halwani, 188.

151 Waugh, 2.

152 Waugh, 3.


156 Sachedina, 777.

157 Sachedina, 777.


159 Waugh, 15.

160 Waugh, 15.

161 Babgi, 121-122.

162 Waugh, 15.

163 Zahedi, Larigani, and Bazzaz, 7.

164 Zahedi, Larigani, and Bazzaz, 7.

165 Waugh, 17.

166 Waugh, 17.

167 Zahedi, Larijani, and Bazzaz, 12.

168 Zahedi, Larijani, and Bazzaz, 12.


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186 Sachedina, 778.
187 Sachedina, 778.
188 Sachedina, 779.
189 Zahedi, Larijani, and Bazzaz, 12.
190 Zahedi, Larijani, and Bazzas, 12.
192 Zahedi, Larijani, and Bazzaz, 13.
195 Khaliq, 57.
196 Khaliq, 57.
197 Khaliq, 52-53.
198 Khaliq, 55-56.
200 Baranowski, 1.
202 Alsossary, While, and Barriball, 126.
207 Kwong and Levitt, 80.
208 Doumanto, 1.
209 Doumato, 1.


211 Said-Foqahaa, 236.

212 Said-Foqahaa, 236.

213 Said-Foqahaa, 237.


216 Rathor, Rani, Shah, Leman, Akter, and Omar, 29.

217 Rathor, Rani, Shah, Leman, Akter, and Omar, 29.

218 Aldossary and Barriball, 126.

219 Kwong and Levitt, 81.


221 Sachedina, 44.

222 Aljawi and Harford, 137.

223 Aljawi and Harford, 138.

224 Al-Alayan and Al-Hazzani, 338-339.


226 Alsirafy, Hassan, and Al-Shahri, 54-55.

227 Alsirafy, Hassan, and Al-Shahri, 54-55.

228 Arabi and Al Shimemeri, 228.


231 Padela, 74.

232 Alamri, 195.
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254 Jonsen, 22.


256 Rivera, Dasta, and Varon, 126.

257 Luce and White, 230-232.


259 Shurgarman, Lorenz, and Lynn, 256.


263 Halpern and Pastores, 67-68.


266 Machato, 3-7.


268 Hester, 18-20; Johanna and Raijammers, 2


270 L. Ganzini, “Care of Patients with Delirium at the End of Life,” *Annals of Long-Term Care* 15, no.3 (2007: 130-147).


273 Papadimos, Maldonado, and Rosenberg, 140-141.

Cook, Damato, and Salmon, 390-391.

Shugarman, Lorenz, and Lynn, 257-258.

Shugarman, Lorenz, and Lynn, 258.

Luce and White, 221-223.

Luce and White, 222.


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Luce and White, 224.

Luce and White, 225.

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Luce and White, 228.

Luce and White, 228.

Luce and White, 229.

Luce and White, 228.

Luce and White, 228.

Luce and White, 224.

Clarfield, Gordon, Markwell, and Alibhai, 1151.


Kwong and Levitt, 82.


Al-Omari, et al, 760.

Al-Omari, et al, 760.

Al-Omari, et al, 761.


Al Omari, et al, 760.

Al Omari, et al, 760.

Al-Omari, et al, 760.

Al-Omari, et al, 761.


Al-Omari, et al, 759.


Al-Omari, et al, 761.
323 Arabi and Al Shimemeri, 230.


330 Takouri and Halwani, 5.

331 Takouri and Halwani, 5.

332 Sachedina, 778.


334 Al Husseini, 17-18.

335 Aljurban, 143.

336 Arabi and Al Shimemeri, 135-136.

337 Arabi and Al Shimemeri, 2006, 228.


339 Aljohaney and Bawazir, 396-397.


341 Van den Branden and Broeckaert, 32.


343 Kasule, 8.

344 Kasule, 9.


346 Society of Critical Care Medicine, 1.
Society of Critical Care Medicine, 1.


Arabi and Al Shimemer, 137.S

Van den Branden and Broeckaert, 33 – 34.


Ibid.

Zahedi, Larijani, and Bazzaz, op. cit., p. 8.


Ibid.

Zahedi, Larijani, and Bazzaz, op. cit., p. 13.


National Palliative Care Research Center, op. cit., p. 2.

Ibid.

Center to Advance Palliative Care, “America’s Care of Serious Illness,” 2015, p. 3. [https://reportcard.capc.org](https://reportcard.capc.org).

Ibid., p. 4.

Ibid.

Ibid., p. 1.


Ibid., p. 5.

Ibid., p. 7.

Ibid., p. 8.


Ibid., pp. 9-10.

Ibid., p. 11.

Ibid., p. 12.

388 National Consensus Project, op. cit., p. 4.


391 Ibid, p. 216.


393 Wolf, op. cit., 116-117.


395 Ibid., 436.


398 Ibid., 3.


400 Ibid., p. 6.

401 Ibid.


403 Ibid., p. 349.

404 National Consensus Project, op. cit., p. 6.

405 Block, op. cit., p. 396.


409 Ibid.

410 Ibid.

411 Ibid., p. 204.

412 Ibid., p. 205.

413 D. Walsh, “The Harry R. Horvitz Palliative Center for Medicine, the Cleveland Clinic Foundation, Pioneer Programs in Palliative Care,” *The Milbank Memorial Fund*, 2000, pp. 1-2.


415 National Consensus Project, op. cit., pp. 6-7.


420 Ibid., p. 4.

421 Ibid., p. 6.


423 Morrison, op. cit., p. 205.


425 R.S. Morrison, op cit., p. 205.

426 McAteer and Wellbery, op. cit., p. 809.

427 Ibid., p. 812.

428 D.M. Aljawi and J.B. Harford, “Palliative Care in the Muslim Majority Countries: The Need for More and Better Care,” 2015, p. 1, http://cdn.interhopen.com/pdfs/27618/InTech-Palliative_C....
429 Ibid.


431 Ibid., p. 16.

432 Ibid.


435 Ibid.


437 A. Bingley and D. Clark, Palliative Care in the Region Represented by the Middle East Cancer Consortium. National Cancer Institute. NIH Publication No. 07-2630, Bethesda, Maryland, 2008, pp. 1-4.

438 Ibid.

439 Al-Alaiyan and Al-Shahri, p. 338.


441 Ibid., p. 5.

442 Ibid.

443 Ibid., p. 10.


445 Ibid.


447 Ibid., p. 46.


449 Al Husseini, p. 2.
450 Al-Dorz, Agathlany, Aldawood, and Arabi, p. 312.

451 Al Shahri & Al Khenaizan, p. 433.


454 Al-Shahri, p. 134.

455 Bullock, p. 84.


458 Ibid.


460 Ibid.

461 Ibid.

462 Ibid.


464 Tayeb, Al-Zamel, and Aboudllail, p. 220.


466 Abudari, p. 4.

467 Ibid., p. 8.


469 Ibid., p. 4.

471 Al Alaiyan and Al Hazzani, p. 339.

472 Alaiyan and Al-Shahri, pp. 162-163.

473 Aljawi and Harford, p. 1.

474 Ibid., p. 2.

475 Alaiyan and Al Shahri, pp. 1165-166.


477 Chan and Webster, p. 18.

478 Silberman and Jaloudi, p. 130.

479 Aljawi and Harford, p. 2.

480 Alaiyan and Al-Hazzani, p. 239.

481 Al-Sahri and Al Khenaizan, p. 430.


484 Luce and Alpers, p. 2.

485 Luce and Alpers, p. 3.


487 Gedge, Giacomini and Cook, p. 215.

488 Gallagher, p. 48.


490 Ackerman, p. 1557.

491 Gedge, Giacomini, and Cook, p. 215.

493 Gedge, Giacomini, and Cook, p. 216.


495 Griffith, p. 1235.

496 Gedge, Giacomini, and Cook, p. 216.


499 Gedge, Giacomini, and Cook, p. 217.

500 Luce and Alpers, p. 2.


502 Gedge, Giacomini, and Cook, p. 217.

503 Ackerman, p. 1667.

504 Willmott, White, and Downie, p. 910.


507 Ackerman, p. 1557.

508 Ackerman, p. 1557.


510 Al Huseini, p. 3.

511 Gedge, Giacomini, and Cook, p. 215.

512 Gedge, Giacomini, and Cook, p. 215.

513 Gallagher, p. 48.

515 Gedge, Giacomini, and Cook, p. 216.


518 Swartz, p.160.


520 Luce and Alpers, p. 2.

521 Luce and Alpers, p. 2.


524 Giovanni, p. 130.


527 Beauchamp and Childress, pp. 60-62.


529 Benson, p 270.

530 Gedge, Giacomini, and Cook, p. 217,


533 Swartz, p. 188.

534 Gedge, Giacomini, and Cook, p. 218.

536 Block, pp.395-396.

537 Qur’an 2: 35.

538 Takouri and Halwani, pp. 16-17.


540 Gouida, Al-Jabbary, and Fong, p. 2150.

541 Rahman, pp. 202-203.

542 Rahman, pp. 204-205.

543 Al-Dorzi, Aljathany, Aldawood, and Arabi, p. 310.

544 Al-Dorzi, Aljathany, Aldawood, and Arabi, p. 311.

545 Al-Dorzi, Aljathany, Aldawood, and Arabi, p. 311.

546 Al-Dorzi, Aljathany, Aldawood, and Arabi, p. 312.

547 Al-Dorzi, Aljathany, Aldawood, and Arabi, p. 312.

548 Takouri and Halwani, p. 18.

549 Takouri and Halwani, p. 19.

550 Takouri and Halwani, p. 320.

551 Takouri and Halwani, p. 320.

552 Takouri and Halwani, p. 320.

553 Al Husseini, p. 2.

554 Silbermann, et al, p. 16.

555 A. Aljohaney and Y. Bawazir, “Internal Medicine Residents’ Perspectives about DNRs,” Journal of Internal Medicine, 2015, 6, p. 393.

556 Aljohaney and Bawazir, p. 397.


Alsolamy, p. 98.

Alsolamy, p. 97.

Zahedi, Larijani, and Bazzaz, pp. 10-11.


Zahedi, Larijani, and Bazzaz, p. 12.

Zahedi, Larijani, and Bazzaz, p. 12.

Zahedi, Larijani, and Bazzaz, p. 12.

Zahedi, Larijani, and Bazzaz, p. 12.

Zahedi, Larijani, and Bazzaz, p. 13.

Zahedi, Larijani, and Bazzaz, p. 13.


Masood, Said, Faris, Al Mussady, and Al Jundi, p. 206.

Van den Branden and Broeckaert, p. 29.

Sachedina, p. 778.

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Khaliq, p. 54.


Terman, p. 22.

Terman, p. 23.

Alamri, p. 196.

Babgi, p. 125.

Al Dorzi, Ajathany, Aldawood, and Arabi, pp. 310-311.

Arabi and Alshimemerli, pp. 227-228.

Al Husseini, pp. 1-2.

Padela, p. 78.

Takouri and Halwani, p. 18.

Bagbi, p. 126.

Alaiyan and Al-Hazzani, op. cit., p. 337.

Babbie, op. cit., pp. 40-42.


Fowler and Hammer, op. cit., p. 127.

Fowler and Hammer, Ibid., pp. 128-129.

Bagbi, op. cit., pp. 120-122.


Zahedi, Larijani, and Bazzaz, op. cit., p. 5.

Zahedi, Larijani, and Bazzaz, Ibid., p.6.


Zahedi, Larijani, and Bazzaz, op. cit., p. 10.

Block, op. cit., p. 394.

Khaliq, op. cit., pp. 52-53.


Gouida, Al-Jabbary, and Fong, op. cit., pp. 2150-2151.

Kwong and Levitt, op. cit., p. 17.

Bagbi, op. cit., pp. 120-122.


Sonfield, op. cit., p. 8.

Ur-Rahman, Arabi, Adhami, Parker, and Al-Shimemeri, op. cit., p. 1278.


Dooley, op. cit., p. 338.

Lange, op. cit., pp. 40-41.


Lange, op. cit., pp. 44-45.

Griffith, op. cit., p. 1234.


Ebrahim, Ibid., p. 194.

Aldossary, While, and Barroball, op. cit., pp. 125-126.

Kwong and Levitt, op. cit., p. 81.

Kwong and Levitt, Ibid., pp. 80-81.

Padela, op. cit., pp. 70-71.


Padela, op. cit., pp. 70-71.

Zahedi, Larijani, and Bazzaz, op. cit., pp. 10-11.

Sachedina, op. cit., p. 42.

Kwong and Levitt, op. cit., pp. 90-91.


Aldossary, While, and Barroball, op. cit., p. 125.

Babgi, op. cit., p.121.

Branden and Broeckaert, op. cit., p. 30.

Takroui and Halwani, op. cit., p. 188.
634 Giovanni, op. cit., p. 129.

635 Lange, op. cit., pp. 102-106.

636 Babbie, op. cit., pp. 102-103.
Bibliography


Center to Advance Palliative Care. (2008). New analysis shows hospitals continue to implement palliative care programs. New York: CAPC.


*In the Matter of Baby K.* 16 F3d 590 (4th Cir 1994).


